

**A Qualitative Exploration of How Young People Experience and Make
Sense of Medically Unexplained Symptoms**

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Abstract

Medically Unexplained Symptoms (MUS), symptoms which do not have a full medical explanation, defy expectations of the illness experience and provide significant challenges to medical services. Clinical guidelines recommend the co-construction of a shared understanding of difficulties. However, this is difficult when symptoms do not have an explanation, and experiences and perspectives of doctors and patients are mismatched.

A qualitative approach was utilised to explore how young people experience and make sense of MUS. Semi-structured interviews were conducted with nine young people who were experiencing symptoms they had been told did not have a full medical explanation.

Inductive thematic analysis identified young people with MUS have difficulty making sense of MUS, found it hard living with MUS and were trying to find a way to manage their symptoms and move forward with their lives. Participants struggled to fit within the medical system. Without a language and way to make sense of their experiences, they struggled to integrate this into their developing identity. Participants assumed a personal responsibility for their recovery but struggled with this in the context of feeling excluded and disempowered.

Implications for clinical practice are considered, recommending discussion of shared uncertainty and ways of managing uncertainty may be helpful for families and professionals. Suggestions are made for future research to extend the current findings and a critical appraisal of the research is provided.

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Introduction

Medically unexplained symptoms (MUS) are surprisingly prevalent in children and adolescents, impair daily functioning and pose a challenge to healthcare systems. They remain poorly understood, with professionals and people experiencing MUS struggling to make sense of them. This study utilises a qualitative design, using semi-structured interviews to explore how young people experience and make sense of MUS. This chapter reviews definitions of MUS, diagnostic criteria and considers the helpfulness of diagnosis. Costs of MUS and impacts on services and families are explored, providing justification for this study. Communication between doctors and patients is reviewed and possible clinical implications are considered. Current research and understandings of how people experience and make sense of MUS are reviewed and critically evaluated. Finally research aims and research questions are outlined.

1.1 Medically Unexplained Symptoms

Various definitions of MUS have been proposed. The range of definitions and conflicts in terminology reflect the difficulty in explaining something that by definition is unexplained. Guidance developed by Improving Access to Psychological Therapies (IAPT; 2008) for the Department of Health defines MUS as: “physical symptoms that have no currently known physical pathological cause” (2008, p. 2).

The Royal College of General Practitioners and Royal College of Psychiatrists’ definition is: “persistent bodily complaints for which adequate examination does not reveal sufficient explanatory structural or other specified pathology” (Chitnis, Dowrick, Byng, Turner & Shiers, 2014, p. 1). This introduces difficulties in defining adequate investigation and does not

specifically include individuals experiencing continuing symptoms following an initial organic disease.

The Diagnostic and Statistical Manual of Mental Disorders-5th edition includes diagnostic criteria for somatic symptom disorder (DSM-V; American Psychiatric Association, 2013). Diagnostic criteria specify the presence of one or more somatic symptoms that significantly disrupt daily life or are distressing, with related excessive thoughts, feelings or behaviours. These may be manifested by persistent, disproportionate thoughts about the seriousness of symptoms, persistent anxiety about symptoms or health, or devoting excessive time and energy to symptoms. (American Psychiatric Association, 2013).

This diagnosis therefore indicates distress above that resulting from the presence of symptoms. The health anxiety, thoughts of symptoms as serious and maintaining behaviours previously categorised as hypochondriasis are also incorporated (Dimsdale et al., 2013). This moves away from defining symptoms by what they are not and aims to provide an explanation. However, this category would not include people with MUS who do not have significantly distressing thoughts and behaviours associated.

There are difficulties in applying these criteria to children and adolescents, especially as thoughts, worries and behaviours regarding symptoms and distress are influenced by parental thoughts and beliefs. However there is some acknowledgement that parents may determine impact on functioning and help-seeking. This is an improvement in terms of understanding symptoms and applications to children (Schulte & Petermann, 2011).

It is generally difficult to apply diagnostic criteria used for adults to MUS in children, largely due to differences in clinical presentation (Weisblatt, Hindley

& Rask, 2011). However, there is a limited child-specific research base and the lack of a developmentally appropriate alternative, meaning adult criteria are applied to children and adolescents (Mohaptra, Deo, Satapathy & Rath, 2014). The lack of clarity regarding definitions and understandings of MUS pose a difficulty establishing MUS as a diagnosis, suggesting a shift from categorical to dimensional diagnostics may be more helpful (Musalek & Scheibenbogen, 2008).

A definition often used in research is: “persistent severe and distressing symptoms that cannot be fully explained by medical knowledge or whose severity cannot be accounted for after medical investigation” (Husain, Browne & Chalder, 2007, p. 2). This definition will be used for this research as it is considered to be the fullest of those discussed, is applicable to children and has fewer assumptions about causes.

Inconsistent terminology leads to additional confusion rather than clarification (Eriksen, Kerry, Mumford, Lie & Anjum, 2013). It is representative of the lack of consensus among professionals about the causes and best intervention or management of MUS (Zavestoski et al., 2004). It also poses the question that if professionals cannot explain, label and make sense of these MUS, how are the people experiencing the symptoms supposed to?

1.2 Challenges to Medicine

By definition, MUS pose significant challenges to western medicine as investigation does not find a cause, a disease cannot be diagnosed and medical treatment is therefore not implicated (Stone, 2013a). The possible pathways for the development of MUS are currently unexplained but these may be psychological, biopsychosocial, related to hypochondriasis or of unknown

pathology. A diagnosis and explanation provide an understanding, language and indicate treatment and are therefore helpful for patients and doctors. However, MUS is used as a diagnosis where no diagnosable disease can be identified. Therefore, MUS does not provide the benefits of a medical diagnosis, rendering the helpfulness of this diagnosis debatable.

MUS also challenge cultural assumptions around illness course. Usually, doctors conduct sufficient investigations to determine whether the patient is sick. However making this decision in the face of uncertainty causes doctors significant anxiety, with doctors worrying they may have missed something important (Stone, 2013a).

1.3 Epidemiology

MUS are fairly common in children and adolescents (Kelly, Molcho, Doyle & Gabhainn, 2010). It is estimated that 2-10% of children in the general population experience pains and symptoms that are likely to be medically unexplained, but these are usually transient and do not affect functioning (Garralda, 2010). Essau (2007) conducted a population-based investigation of adolescents and reported 12.2% were likely to be experiencing MUS, with a higher prevalence in females. Vila, Kramer and Hickey (2009) found 10% of children reported MUS, with a higher prevalence in females. Symptoms were associated with emotional symptoms and impairment in daily functioning. MUS are estimated to account for up to 50% of new medical outpatient visits (Mohaptra et al., 2014).

1.4 Impact of Medically Unexplained Symptoms

MUS can significantly impact on daily functioning and all areas of daily life. Konijnenberg et al. (2005) found children with MUS had substantial impairments in social functioning, sporting activities, school attendance and

sleep. In addition, in a prospective study following children and adolescents for up to 15 years, MUS in childhood and adolescence was found to increase the risk of MUS in adulthood (Walker, Dengler-Crish, Rippel & Bruehl, 2010). This suggests MUS can have a long-term impact over the lifespan.

Patients with MUS have poorer quality of life and higher costs, including use of healthcare resources, lost productivity in work and at home in comparison to other patient groups (Zonneveld, Sprangers, Kooiman, van Spijker & Busschbach, 2013). The authors highlight that patients with MUS self-reported their quality of life to be mainly decreased by limitations in functioning due to physical health.

Therefore, MUS have a significant impact on the lives of individuals and families. Research often utilises cross-sectional quantitative methodology, providing an overview across a large number of people and providing comparisons rather than exploring in-depth effects of MUS for individuals and families.

1.5 Costs of Medically Unexplained Symptoms

MUS are estimated to cost the NHS £3.1 billion annually (Bermingham, Cohen, Hague & Parsonage, 2010) and account for 25% of outpatient care and 35-53% of new hospital outpatient referrals (Gathogo & Benjamin, 2012). Those experiencing MUS have been found to have 50% more consultations and 50% more healthcare costs than people with symptoms with a full medical explanation (IAPT, 2008).

The first point of contact in England is usually primary care, but clinicians report difficulty managing patients with MUS, anxiety around providing a good level of care and a lack of training or professional guidance

(Plymouth Project, 2009). This can result in significant burden on the healthcare system with consultations from different specialists and ineffective investigations and treatments (Sumathipala et al., 2008). Patients with MUS are high healthcare resource users and have a major impact on the health economy and health outcomes. This highlights the importance of exploring new ways of working with this population to reduce costs and demands and improve outcomes.

1.6 Medically Unexplained Symptoms in Children and Young People

MUS in children differ from MUS in adults, and so it is necessary to consider MUS in children separately. Common MUS in children include pain, fatigue, gastrointestinal symptoms and neurological symptoms (Eminson, 2007).

It is important to consider MUS in the context of the child's emotional, cognitive, social and physical development (Edwards & Titman, 2010). As children grow, their bodies are affected by substantial changes, affecting physical appearance and neuro-endocrine systems (Eminson, 2007).

Children live within the context of their family, and during childhood and adolescence family influences significantly impact on every aspect of their lives. Family understandings, beliefs and narratives influence the interpretation and experience of symptoms and determine help-seeking, consultation of professionals, and management of symptoms (Weisblatt et al., 2011). Attribution of symptoms, response to illness and expression of emotional distress are largely determined by family factors (Eminson, 2007). For example, if a child experiences stomach pain, a parent may interpret this as a symptom of stress and seek to reduce the stress or support the child. If a parent interpreted the pain as a symptom of serious illness, they would seek medical advice, investigations and treatment (Garralda, 2010).

Parental mental health is an important factor in the experience of the child (Edwards & Titman, 2010). Parental depression and anxiety have been found to be associated with child recurrent abdominal pain (Campo et al., 2007). Craig, Cox and Klein (2002) found that children of mothers with MUS were more likely to have health problems and increased consultations with family doctors. This suggests that having a mother with MUS increases the likelihood of a child experiencing difficulties, although it is unclear if the health problems reported were MUS or had an organic pathology. This may represent the mother having heightened sensitivity and attention to illness or a perspective of all symptoms as a sign of illness.

Parental anxiety often models anxiety for young people, meaning they develop beliefs that a certain situation or trigger is worrying (Cresswell & Willetts, 2007). However, Craig et al. (2002) relied on parental report and therefore represent the views, attitudes and beliefs of the mother rather than the experiences and understanding of the child. It would be important for future research to collect data from children.

Griffin and Christie (2008) describe how if care is transferred to a psychiatric team following investigations, families may experience this as moving towards belief of a cause within family functioning, and become defensive, resulting in difficulties in engagement. However, this could be considered in the context of the family system, with parents determined to get the best for their child, and acting from concern. Griffin and Christie (2008) highlight the importance of consideration of family and systemic factors throughout assessment, building an understanding and in intervention.

1.6.1 Development of identity

Traditionally, establishing self-identity was viewed as a central task of adolescence (Erikson, 1968). However, it is now acknowledged that development of identity begins before and continues after adolescence (Meeus, 2011). Personal identity develops progressively through adolescence with continuity of identity and coherence of life story growing throughout (Meeus, 2011). It is unclear how young people can incorporate MUS into their identity and life story, and likely that how they experience and make sense of symptoms will impact on this.

The illness representation model of illness highlights the importance of making sense of illness and identity. This suggests an individual constructs an internal representation of physical or psychological symptoms they are experiencing (Meyer, Leventhal & Guttman, 1985). An individual's representation of illness provides context for their ways of preventing or managing illness.

Five elements contribute to the illness representation: identity, cause, consequences, time line and controllability or cure. This illness representation contributes to emotional reactions, coping strategies and appraisal of these. Difficulties can arise when illness representations conflict with self-identity, or cannot be readily incorporated, leading to individuals having to develop new rules (Brownlee, Leventhal & Leventhal 2000).

Therefore this suggests patients with MUS may have difficulties making sense of their illness. Without a meaningful narrative for their illness, it is difficult for individuals to incorporate their illness into their identity and view of themselves (Stone, 2013a). This may impact on identity development, coping,

functioning, appraisal of symptoms and responses to symptoms (Brownlee et al., 2000).

In addition, in adolescence, friendships become more important and complex (Brown & Larson, 2009) but contribute to identity formation (Jones, Vaterlaus, Jackson & Morrill, 2014). Therefore it is important to explore how young people specifically experience and make sense of MUS in the context of developing identity and peer relationships.

1.7 Psychological Models

A number of psychological models have been applied to understanding illness and MUS. These seem to be an attempt to find an explanation for symptoms which by definition are unexplained. Evidence is often either lacking or contradictory (Rief & Broadbent, 2007). It is not possible or considered valuable to comprehensively review all models proposed for MUS. The following models are considered the most relevant for this project in considering experiences and making sense of MUS.

1.7.1 Biopsychosocial model.

Engel (1977) proposed the biopsychosocial model, which conceptualises illness as resulting from biological, psychological and social factors. This model aims to encourage doctors to consider the reasons a patient is seeking care and use this to guide intervention. Therefore information regarding psychosocial issues is considered as valuable as medical investigations. The model was intended to be holistic and challenges the traditional medical paradigm. It offers some explanation for why some patients experience illness, whereas others with similar conditions regard these as simply challenges of life (Engel, 1977).

However this model has not been widely accepted by medical science (Van Oudenhove & Cuypers, 2014).

In addition, the model is difficult to define and test due to its flexibility and humanistic qualities (Smith, Fortin, Dwamena & Frankel, 2013). A multitude of factors may be relevant to an individual, making the operationalization of the model in clinical practice difficult. Smith et al. (2013) have attempted to address these limitations, suggesting an individualised, specific representation of the biopsychosocial model is developed in each doctor-patient consultation.

Butler, Evans, Greaves and Simpson (2004) argue that more emphasis on the complex reciprocal interactions between factors that form the experience is necessary. Indeed, for a fuller understanding, symptoms should be considered as a part of a human within a psychosocial context (Eriksen et al., 2013).

The biopsychosocial model is considered the dominant model in understanding MUS (Fava & Sonino, 2009; Ghaemi, 2009). It allows construction of a shared narrative for understanding the cause and maintenance of symptoms, in a way that is acceptable to the patient and family (Kirmayer, Groleau, Looper & Dao, 2004).

1.7.2 Uncertainty in illness.

Mishel (1981) proposed the theory of uncertainty in illness, where individuals are experiencing difficulty in structuring a meaningful account and understanding of illness related events, to provide an explanation of adjustment to acute illness. This framework suggested factors including ambiguity concerning the condition, lack of information about the diagnosis, unpredictability of prognosis, and complexity regarding treatment and the

healthcare system act as antecedents of uncertainty, which contributes to difficulties making sense of and adjusting to symptoms experienced (Mishel, 1981).

This theory was reformulated to include the experience of those experiencing chronic illness and living with on-going uncertainty (Mishel, 1990). This updated theory reflects an understanding that uncertainty may continue and suggests accepting uncertainty may be more adaptive than attempting to resolve uncertainty. However, this is a very difficult process that gradually evolves over time and may not be reached by many (Mishel & Clayton, 2003). Illness uncertainty has been found to be associated with decreased quality of life (Suzuki, 2012; Wallace, 2003), psychological distress and difficulties with adjustment (Decker, Haase & Bell, 2007; Mullins, Chaney, Balderson & Hommel, 2000).

Hansen et al. (2012) conducted a systematic review of qualitative research exploring the experience of uncertainty in illness. They found uncertainty was strongly associated with unknown aetiology of symptoms, unknown prognosis, unclear role, professionals' lack of understanding and knowledge, limited information, and a disorganised, fragmented healthcare system. Those experiencing uncertainty described considerable emotional burden and stress, feeling constantly alert for symptoms or suggestions of deterioration, a loss of control and need to avoid uncertainty. They conceptualised uncertainty as a major, multifaceted and regularly changing problem, with some understanding symptoms and development of symptoms as attempts to avoid or manage this uncertainty.

Although not an explanatory model of the development of symptoms, this model provides some understanding of the experience of MUS. Through this we may also begin to understand the maintenance of MUS. The predicted antecedents of uncertainty particularly resonate with the characteristics of MUS. The systematic review described included articles with a range of diseases, symptoms, ages and genders but the findings describe commonalities experienced across the range, and it is expected these would also be similar for MUS. For example, a lack of a definite comprehensive diagnosis or label, understanding and explanation of symptoms, complexities in the healthcare system and unclear prognosis are all features particularly pertinent to MUS. The combination of these factors increases uncertainty and provides barriers to accepting and integrating uncertainty into one's life. This predicts difficulties adjusting and coping and thus perpetuates existing difficulties, including symptoms. Reviewing this model has led to consideration of any role uncertainty may play in this research. Ideas of uncertainty in planning this research, and considering application of ideas and models were included in the research reflective log. It is considered likely that people with MUS may experience uncertainty, which may contribute to difficulty making sense of symptoms, and affect the experience of MUS.

1.7.3 Cognitive behavioural model.

The cognitive behavioural model was originally developed to explain development and maintenance of emotional distress (Beck, 1976). It has since been applied to a range of conditions, including MUS. The model identified a variety of factors that interact to cause and maintain distress and symptoms. The model proposed developmental predispositions, precipitants and perpetuating

cognitive, behavioural, affective and physiological components (Beck, 1976).

The factors and interaction of these may be different for each individual.

Various factors have been identified as important in the predisposition to developing MUS, including genetic predisposition, early experience of adversity and sensitivity to threat and viruses (Deary, Chalder & Sharpe, 2007). When combined with precipitating events, such as life events or dilemmas (Hatcher & House, 2003), this is likely to cause distress which may trigger physiological activation. With lower distress tolerance, this can be manifested in bodily sensations interpreted as symptoms.

The cognitive, emotional and behavioural processes are similar to in hypochondriasis (Dimsdale et al., 2013). Cognitive processes including selective attention to negative stimuli or symptoms lead to increased symptom perception (Rief & Barsky, 2005). Attention, misattribution and misinterpretation contribute to symptom generation and maintenance (Brown, 2004). Worry or rumination regarding life events or responses maintains physiological activation (Brosschot, Pieper & Thayer, 2005). A complex interaction of cognitive, behavioural, affective and physiological responses follows, leading to the development of a perpetuating cycle which maintains symptoms, distress and disability (Deary et al., 2007).

A strength of the cognitive behavioural model is the individuality and flexibility allowing recognition of the different circumstances and the combination of factors affecting the individual. However, this does render the evaluation of this interaction of factors and maintaining cycle very difficult. Regardless, there is a general consensus that the cognitive behavioural model offers a useful explanatory model of MUS (Deary et al., 2007; Mai, 2004;

Neimark, Caroff & Stinnett, 2005). Yet this model focuses on the individual, with limited consideration of environmental, family or social factors surrounding the individual.

1.7.4 Systemic and family factors.

Weisblatt et al. (2011) propose the interactions of factors within the child, within parents, within school and the wider environment, and within medical system factors can explain the development and maintenance of MUS in children. All factors are assumed to include both protective and pathogenic factors. Although this allows development of an individual formulation for the child, the amount of different combinations and interactions result in a model that is very difficult to test empirically.

Eminson (2007) proposes a similar model, but excludes school and wider systemic factors. Factors within the child, parent and professionals interact, with specific interactions between children and parents, and parents and the healthcare system. Each level includes predisposing, precipitating and maintaining factors and processes that may exacerbate or increase the experience of symptoms, fear of disease and level of impairment, or alternatively may contain and reduce these. This model would again be difficult to test empirically. However, it is based on a review of the research and evidence base for children with MUS, with the model an integration of the findings of this review. The consideration of both positive and negative factors at each level, interactions of these and effects on experience are interesting, and this is a model that may be understood and accepted by families.

Importantly, both models include consideration of parental factors and interactions with other factors. As discussed, parents have a significant impact on

all aspects of a child's life, and how they make sense of and attribute symptoms affect how these are understood and any help-seeking behaviours.

Claar, Simons and Logan (2008) investigated parental responses to child pain behaviour. They reported that for children with higher levels of emotional distress, maladaptive parental responses to pain were associated with increased somatic symptoms and disability. Maladaptive responses included criticism, discounting the pain, increased attention to the pain and granting special privileges.

Walker et al. (2006) found that parental attention significantly increased the symptoms in both well children and patients, whilst parental use of distraction decreased symptoms, according to child report. However, parents rated distraction as having a greater negative impact on children than attention.

This study highlights the difference between child and parent rating. This has important therapeutic implications, suggesting parents and children may understand positive change differently. The study had many strengths, using random allocation to condition and monitoring adherence to condition. They also compared a large sample of children with and without MUS, using a task to provoke symptoms. In addition, they collected data from parents and children, highlighting differences in report. However, the symptom provocation task resulted in mild discomfort, and so did not replicate the experience of pain. Also, differences between mothers and fathers were not analysed. The study was cross-sectional and so examined short-term effects of parental responses, but suggests examination of longer-term effects would be beneficial.

1.7.5 Summary.

Overall, a number of psychological models have been applied to attempt to explain and understand MUS. It is unclear if any of these models and understandings are endorsed by patients with MUS and their families, or reflect their understandings. Different models and understandings lead to a range of interventions and treatment packages. Eriksen et al. (2013) accurately summarise the current position: “altogether, these different attempts to deal with the medically unexplained reveal a certain degree of bewilderment” (p. 6).

1.8 Interventions

1.8.1 Guidelines.

Clinical guidelines provide recommendations for intervention for patients with MUS. Guidelines from the Dutch Association of General Practitioners (NHG) are often used, and suggest physicians need to work with patients to co-create an understanding of symptoms in a way that makes sense to the patient (Olde-Hartman, Blankenstein et al., 2013). In addition, guidance produced by IAPT (2008) highlights frequent co-morbid anxiety or depression which is often ignored, and recommends screening and intervention as necessary. They also identify barriers to treatment, often inadvertently created by professionals and systems, including prioritising physical health problems and limited knowledge regarding mental health and interactions with physical health. They recommend increasing referrals to mental health services, which should be located within physical health services to acknowledge the physical symptoms (IAPT, 2008). However, they do not provide recommendations for the intervention to be offered, and there is little published guidance for this.

1.8.2 Engagement.

A qualitative exploration into therapeutic engagement with adults with MUS identified the explanation of symptoms and constructing a shared understanding as the most important factor in building engagement (Chew-Graham, Brooks, Wearden, Dowrick & Peters, 2011). Patients needed to feel believed and accepted, and the model held by the patient had to match the treatment model implicated.

Therapists interviewed reported an initial difficulty forming a therapeutic alliance, with jointly constructing understandings and empowering the client identified as the most important aspects (Luca, 2012). Jointly constructing a shared understanding can be a difficult process to negotiate and requires skill and experience, particularly in managing threats to the therapeutic relationship, with failure to achieve this resulting in disengagement (Luca, 2012).

Engaging families with services is essential for the treatment of a child experiencing MUS, but may be very difficult (Eminson, 2007; Garralda, 2010; Hardwick, 2005; Weisblatt et al., 2011). Following medical investigation, care of the child is often transferred to psychiatric services, which may be strongly resisted by families with a medical understanding of the symptom, establishing challenges in developing positive family-team alliances. Families report feeling blamed and become defensive, hypervigilant to criticism and therefore less open to working collaboratively (Griffin & Christie, 2008).

Containing parental fears and taking account of their beliefs about possible undiscovered organic pathology is essential for engagement (Hardwick, 2005). Mohaptra et al. (2014) recommend any treatment should involve developing partnerships with the child, family and wider system and working

together to collaboratively find a way to recover and regain functioning that is acceptable to the child and family.

1.8.3 Psycho-education.

Psycho-education includes explanations of difficulties, their possible causes and consideration of how these are maintained and can be used across models. It is often used to begin constructing a shared understanding of difficulties and symptoms. Mayor et al. (2012) found that following communication of diagnosis including psycho-education techniques, some patients showed a reduction in symptoms. However, self-report measures of health and functioning, health service utilisation or symptom attribution, showed limited change, suggesting patients themselves did not notice significant improvement.

An extension of this examined an additional psycho-education intervention. Although 29 participants completed baseline measures, only 13 completed follow-up measures seven months after diagnosis (Mayor et al., 2013). It is unclear how many participants completed the intervention, or if this high attrition rate suggests the intervention had low tolerability.

However, this research group did conduct a qualitative component; exploring participants' perceptions following the intervention, reported by Baxter et al. (2012). They identified a variety of themes as important to participants, including getting answers, doubting the diagnosis and finding a way forward. However, there was considerable individual variation in response, with some participants showing changed perceptions and enhanced understanding while some continued to seek medical investigations. They found no clear links between increased understanding and acceptance of explanation and a perceived improvement in symptoms. Also, the intervention was not appealing for many

with only 24 of 39 patients offered the intervention consenting to begin (Baxter et al., 2012).

1.8.4 Cognitive behavioural therapy.

Cognitive behavioural therapy (CBT) follows from the cognitive behavioural model described above and begins with developing a formulation, a coherent multi-factorial shared understanding of the difficulties the individual is experiencing that forms the rationale for intervention (Deary & Chalder, 2006). Interventions focus on the perpetuating cycle believed to be maintaining the difficulties for the individual, working towards goals agreed collaboratively (Deary et al., 2007). Although CBT contains core principles and techniques, it allows modification for specific groups based on formulation, making it ideal for a heterogeneous group such as MUS (LaFrance et al., 2013).

A number of review studies suggest efficacy of CBT for MUS, demonstrating improvements in symptom levels, social and physical functioning and psychological distress (Allen & Woolfolk, 2010; Kroenke, 2007; Kroenke & Swindle, 2000; Nezu, Nezu & Lombardo, 2001; Raine et al., 2002; Sumathipala, 2007). In addition, Sharma & Manjula (2013) conducted a review and concluded there is a strong and consistent evidence base for the efficacy of CBT replicated across studies and reviews. However, this review was not systematic and it was unclear how studies were selected for inclusion. Effect sizes and number needed to treat analyses are not considered, reducing the meaningfulness of comparisons across studies. When effect sizes are considered, there seems to be small to moderate effect sizes, suggesting although CBT can be effective, there remains space for improvement (Pieh et al., 2013).

1.8.5 Multidisciplinary treatment packages.

Multidisciplinary treatment packages are usually based within a biopsychosocial approach. Professionals involved may include psychology, nursing, social work, physiotherapy, psychiatry and family therapists. This approach is generally used within inpatient settings where all aspects of the environment are considered and structured therapeutically.

Schaefer et al. (2012) report the findings of a multidisciplinary working group and a systematic literature review, suggesting a biopsychosocial perspective allows professionals and patients to work together. They recommend psycho-education plus physical and social activation for those with mild impairment. Those experiencing more severe difficulties require a coordinated multidisciplinary approach including graded activation, psychotherapy and a range of interventions from different professionals dependent on the individual (Schaefer et al., 2012). This review has many strengths, including a range of perspectives and evidence and transparent reporting of the research process and findings, providing a high standard of evidence.

1.8.6 Family interventions.

Griffin & Christie (2008) describe a multidisciplinary inpatient treatment programme which includes specific family and systemic components. They argue MUS represent bodily communication of emotional distress, with the communication determined largely by family and systemic factors. They aim to communicate their belief in the reality of symptoms, explicitly connect the physical and emotional, and develop shared goals towards recovering family functioning. Parents and family members are invited to act as part of the team, including in treatment planning.

However the article is descriptive, does not discuss the evidence-base and does not evaluate the programme. They conclude the treatment is effective, but do not report any formal measures of outcome. In addition there is no comparison treatment; perhaps the inpatient component alone may explain some improvement. It is unclear how many children complete the treatment, if any withdraw or if there is an effect on MUS. However goals are agreed collaboratively and the treatment is tailored to the family and young person, resulting in person-centred outcomes.

1.8.7 Summary.

This research reviews a small number of interventions used with individuals with MUS. Research suggests a variety of interventions can be effectively used with people with MUS.

However research is currently sparse. Existing research has a number of limitations, including a lack of transparency in reporting. When reported, effect sizes are varied and suggest interventions are only effective for some individuals. A wide variety of outcome measures are used, with varying levels of appropriateness. Interventions may focus on return to functioning, reduction of symptoms, adjustment, and understanding of symptoms among other outcomes (LaFrance et al., 2013). However there is limited consideration of the value of these outcomes to participants and their families.

Many participants withdraw from research, or do not complete interventions, suggesting low tolerability of interventions. Unfortunately, data are rarely collected on participant experience of intervention.

A critical evaluation and synthesis of research examining families' and professionals' perceptions of healthcare services for children and young people

with MUS identified a lack of quality, rigorously conducted research (Hinton & Kirk, 2015). They identified communication, health beliefs of the family and professionals, healthcare settings and knowledge were important influences on perceptions of services. The review suggested many families reported dissatisfaction with services, which may affect engagement. Hinton and Kirk (2015) conclude the lack of research to inform high-quality, evidence-based practice results in a risk of young people with MUS receiving inadequate care and support.

1.9 Service Pathways

There are few established guidelines for diagnosis and treatment of MUS, with significant gaps identified (Plymouth Project, 2009). Pathways to care are unclear, and understanding in assessment and management of MUS can vary considerably. Inconsistency within and across services is a significant issue, resulting in increased costs, use of healthcare resources and negative impact on patient outcomes (Plymouth Project, 2009).

Patients and families are likely to have different experiences of consultations, with differing outcomes. Ring, Dowrick, Humphris, Davies and Salmon (2005) describe many General Practitioners (GPs) face uncertainty with these patients and worry about missing something important, often resulting in a sense of dissatisfaction from both GPs and patients, with families left feeling unsupported and confused. This uncertainty frequently leads to extensive and unproductive investigations (Ring et al., 2005), which are costly, often painful and reinforce thoughts of serious illness.

In addition, children with MUS frequently experience physical investigations as more painful, with pain for a longer duration than children experiencing

similar symptoms from a physical, medically explained disease (Crandall, Halterman & Mackner, 2007). Guidelines published by the Royal College of General Practitioners and Royal College of Psychiatrists (Chitnis et al., 2014) therefore recommend positive risk management. They argue that a consensus of good practice recognises that not investigating may be best for the family. However, it is unclear how much positive risk management is used in practice.

The Plymouth Project (2009) summarises the current status well, describing MUS as

common, associated with significant distress, and can result in unnecessary and costly referrals, diagnostic tests and even operative procedures. The current system is inefficient; resulting in unnecessary stress and dissatisfaction for both clinicians and patients in addition to the use of a disproportionate amount of time and resources (p. 2).

Within this, families risk being lost within the system, and the focus is on costs and outcomes rather than the experiences and accounts of individual patients. Therefore it is important to understand the experiences and perspectives of those with MUS and their families.

1.10 Young People and Healthcare Services

Young people usually access healthcare services through their parents, with parents effectively acting as gatekeepers (Eminson, 2007). Parental beliefs and family narratives about the causes of symptoms determine help-seeking and consultation behaviour (Weisblatt et al., 2011). When help is sought, physical dependence on parents and difficulties in the complexity of negotiating consent in young people prevents individual consultation. Parents often answer questions

in consultation and provide a history and description of the symptoms, and their accounts will be influenced by their own beliefs and interpretations of the symptoms (Weisblatt et al., 2011). Advice for management and reassurance is largely directed to parents and doctors convince parents of investigations required or not to gain their consent. This results in consultations addressing concerns of parents, and their understanding of the problem and appropriate intervention more than those of the young person (Eminson, 2007). Therefore it is important to consider the young person within the context of their family.

However, research has found significant differences in the reporting and understanding of parents and young people. Garber, Van Slyke & Walker (1998) found that mothers of children with MUS reported more child somatic and depressive symptoms than the young people themselves did. Interestingly, as maternal distress increased, so did their reporting of symptoms. It is not possible to infer causation from this research, but this suggests an interaction between parents and young people where level of distress is important.

Taylor Szatmari, Boyle and Offord (1996) found limited agreement between parents and young people regarding the presence of individual MUS, with parents reporting lower levels of symptoms and lower levels of loss of function than the young people, when compared directly as a parent-youth pair. Parental report and understanding is an essential part of understanding the context of the problem. However attempts should be made to elicit an account of the experience of young people, their understanding of the problem, its history and their beliefs.

Paediatricians usually determine referrals to other services for investigations or to psychology or liaison services following sufficient investigations to feasibly exclude organic pathology. However there is a wide

variation in their attitudes to MUS and referral rates to appropriate services (Weisblatt et al., 2011). This may result in extensive and unnecessary further investigations, discharge or disengagement from services.

1.11 Communication of Medically Unexplained Symptoms

Careful consideration is needed for communication of results of investigations when these suggest no full medical explanation for symptoms. NHG guidelines suggest physicians need to work with patients to co-create an understanding of symptoms in a way that makes sense to the patient (Olde-Hartman, Blankenstein et al., 2013). This can be the first step in symptom management or recovery and can facilitate engagement with services and appropriate interventions (Kanaan, 2007). However, this may be difficult in practice, especially when both parties are unaware of the others' perspectives and understandings. In addition, MUS cannot be explained in the way doctors have typically been trained to explain illness (Hemingsen & Priebe, 1999). Medical consultations are considered from the perspective of both doctors and patients.

1.11.1 Doctors' perspectives.

Doctors report finding discussing a conclusion of MUS particularly difficult (Kanaan, Armstrong & Wessely, 2009). Doctors had a desire to maintain therapeutic engagement and wished to avoid confrontation. They suggest doctors are trying to guess an acceptable explanation for their patient, and are assuming this is very different to the perspective they hold themselves, thus making the interactions more difficult (Kanaan et al., 2009).

Furness, Glazebrook, Tay, Abbas and Slaveska-Hollis (2009) explored perceptions of paediatric healthcare professionals working with children with MUS and found professionals experienced uncertainty in initiating discussions

around MUS, reporting concern of upsetting families and disrupting the therapeutic relationship. They suggested staff identified children with MUS as having complex needs and perceived these needs as resulting in extra demands and anxieties, especially regarding communication. Staff highlighted their recognition of the importance of working with a family in addition to the individual child but experienced particular difficulty when the needs of children and families differed. Staff reported an awareness of complex family dynamics and feeling powerlessness and uncertainty in the face of this, expressing a desire for specialist information and training. However, although providing valuable insight into the healthcare experience from the staff perspective, only 50% of staff invited to respond did so, and of these only a minority agreed to discuss their concerns further. Therefore it is unclear how representative this perspective was of all staff.

Monzoni, Duncan, Grunewald and Reuber (2011a, 2011b) explored doctor-patient interactions when a doctor was communicating a diagnosis of MUS. They suggest doctors use increased effort in formulation and accounting, especially when discussing aetiology of symptoms and making recommendations of psychological intervention (Monzoni et al., 2011a). Interestingly, doctors also used these activities at the start of conversation and when patients were aligned with the doctor, suggesting doctors may have concern and feelings of defensiveness prior to the consultation (Monzoni et al., 2011a).

However Monzoni et al. (2011b) found interactional resistance in consultations, particularly when aetiology of symptoms and treatment recommendations were discussed. Interestingly this relates to when doctors were

found to make more effort (Monzoni et al., 2011a). Perhaps doctors' prior concerns or defensiveness may therefore be based on previous experience.

Resistance including challenges, disagreements and rejections, silence, use of minimal responses or lack of engagement with the interaction was demonstrated. Monzoni et al. (2011b) suggest doctors attempt to avoid resistance, as it is unpleasant. Yet, demonstration of resistance allows doctors to discuss individual concerns and rejections or challenges and facilitates open discussion. Monzoni et al. (2011b) argue their research demonstrates that concerns doctors have around discussing MUS may be justified.

1.11.2 Patients' perspectives.

In comparison, research investigating patients' perspectives of consultations is limited. Carton, Thompson and Duncan (2003) conducted semi-structured interviews and found most participants had a poor understanding of their diagnosis. This suggests the majority of patients are unable to develop a coherent explanation for their symptoms from medical consultations. This qualitative research allowed exploration of individual views without the rigidity of set answers. Time period between consultation and interview varied and it is unclear if any confusion or understanding may be due to time lapsed post-consultation.

Analysis of video-recorded consultation suggested GPs allow patients opportunities to tell their story but their concerns, accounts or reasons for seeking support were not discussed in a structured manner (Olde-Hartman, van Rijswijk et al., 2013). Patients generally initiated discussion of their ideas, beliefs and concerns. Although GPs generally gave lengthy explanations of the causes of symptoms, these rarely incorporated the patients' ideas and accounts they had shared (Olde-Hartman, van Rijswijk et al., 2013). This meant patients did not

feel listened to and struggled to build a coherent narrative to share their experiences and accounts.

Difficulties in communication with doctors were described as contributing to the overall experience of MUS (Green, Payne & Barnitt, 2004). This may be as the patients' story of symptoms and struggles does not elicit the expected doctors' story of diagnosis and treatment, compounded by incoherent stories being difficult for doctors to hear (Nettleton, O'Malley, Watt & Duffey, 2004).

Salmon, Peters and Stanley (1999) interviewed adults with MUS and found that explanations by doctors often conflict with patients' own thinking. This resulted in many individuals experiencing the explanations as rejecting the reality of symptoms, reducing trust in their doctor and resulting in disengagement from services. Allegretti, Borkan, Reis and Griffiths (2010) interviewed patient-doctor dyads and found dyads shared convergent stories around the severity of illness, existence of many barriers to care and lack of effective treatments. However, they highlighted that patient-doctors stories around models of symptoms and illness, the importance of a definitive diagnosis and treatment goals and expectations differed and often conflicted. Indeed, several doctors interviewed were critical of their patients' ability to conceptualise their symptoms and show clinical improvement (Allegretti et al., 2010).

This suggests the patient's perspective is often being missed within consultations, with assumptions held by professionals guiding interactions, resulting in the patient and their views being lost. Interestingly, this seems to be reflected in the research literature, with limited value placed on patient perspective or experience. Patients with MUS also report dissatisfaction with

consultations when ideas and explanations expressed by doctors do not match their own (Green et al. 2004).

1.11.3 Implications.

Salmon (2007) found consultations about MUS often involve contests between doctors' and patients' authority, with each occupying different conceptual ground. In western medicine, patients and doctors share a common language of causality, where symptoms have clearly defined causes. When this is challenged, contest needs to be avoided by finding a common conceptual ground where both doctors and patients can discuss symptoms. If this is not achieved, or perspectives cannot be shared, this contest and strategies employed may define clinical care more than clinical need (Salmon, 2007).

Therefore difficulties in interactions are negatively impacting on patient care. Research suggests doctors manage their anxiety around these interactions by requesting further investigations to address their worry about missing illness and to reduce uncertainty (Kanaan et al., 2009). They also adapt explanations to patients; giving an explanation they believe would be more acceptable to the patient, rather than an explanation they truly believe. In addition, in correspondence to referrers, doctors detailed the explanations given to the patient, expecting referrers to understand the explanation they held by inferring from what was not written (Kanaan et al., 2009).

Furthermore, Page and Wessely (2003) argue well-intentioned actions of doctors may be exacerbating or maintaining MUS, by requesting further investigations, withholding information they believe patients do not want to hear, or not suggesting plausible hypotheses which make sense to the patient. Salmon, Ring, Dowrick & Humphris (2005) found that although patients with MUS often

sought explanation and emotional support, they were instead given physical interventions, including medications. Disproportionate amounts of physical interventions are often reported by doctors to be due to patients' understandings of a physical cause and demands for physical intervention (Ring et al., 2005). However, analysis of 420 consecutive consultations involving MUS suggested physical intervention was proposed more by GPs and most GPs suggested a physical disease although they may allude to other explanations. In contrast, patients' cues regarding an alternative explanation or needing an explanation were largely ignored, with few GPs attending to cues or empathising with patients (Ring et al., 2005).

Disengagement is possible following difficult interactions or where different perspectives are held (Kanaan, 2007; Kirmayer et al., 2004). Anxiety experienced by doctors and patients also results in difficulty managing a transition from investigation to coping and improving functioning (Stone, 2013a).

1.12 Experiences of Medically Unexplained Symptoms

Several research studies exploring the experiences of adults with MUS have been conducted. These have included adults with unexplained pain, neurological symptoms, gastrointestinal symptoms and fatigue. These have generally used qualitative methods of analysis, allowing exploration of experience, meanings and understandings of people from their individual perspectives (Lamb, Bower, Rogers, Dowrick & Gask, 2012). The assumption is that research is inductive and interpretative as researchers cannot know before asking how individuals understand and experience the world.

Interviews aim to access the individuals' interpretation of their own experiences that are told to the interviewer. However, researchers interpret this relation of experience, and relate this to other experiences communicated. Studies reviewed expressed the researchers' interpretations of accounts, but provided direct quotations from interviews to demonstrate evidence and provide context. Therefore these published interpretations are assumed to provide some insight into individuals' accounts and experiences. Articles were reviewed separately to identify themes and then comparisons drawn across articles.

An overarching issue identified was the impact of MUS on identity and the view of the self and difficulties negotiating a view of the self and place in the world when experiencing MUS. At times, symptoms may overwhelm identity (Nettleton, 2006), or not fit with the identity a person has constructed (Arroll & Senior, 2008). This is exacerbated without a label or diagnosis for their symptoms to incorporate these into their self-view (Green et al., 2004).

1.12.1 Confusion.

Accounts of experiences were complex, sometimes unclear, with difficulties constructing a coherent timeline, defining the beginning, progress and any actual or imagined end, a sense of confusion and lack of clarity (Green et al., 2004; Nettleton et al., 2004; Nettleton, Watt, O'Malley & Duffey, 2005).

Individuals highlighted uncertainty associated with lacking a diagnosis or coherent explanation (Nettleton, 2006); regarding prognosis (Green et al., 2004); being caught in a "diagnostic limbo" (Nettleton et al., 2004) and leading to feelings of helplessness (Arroll & Senior, 2008). Many described variability in symptoms or periods of remission contributing to unpredictability, uncertainty and enhancing confusion (Arroll & Senior, 2008; Green et al., 2004).

Some experienced frustration living with an illness that cannot be deciphered or treated, and found themselves stuck experiencing symptoms but not feeling accepted by the medical system (Nettleton et al., 2004). They experienced difficulties entering the sick role, and were unable to be ‘successfully ill’; where they are ill but understanding and managing symptoms (Frank, 1997). Confusion and uncertainty meant some were unsure if they were ill, or how to communicate this, because: “how can you discuss something that you feel, but which isn’t there?” (Nettleton et al., 2005, p. 207).

1.12.2 Social relationships.

Relationships ranged from being characterised by a lack of understanding, recognition and support, to recognition but difficulty with dialogue and mutual understanding (Raheim & Haland, 2006). Many individuals chose to conceal their condition as they were concerned about what to tell others, thought others did not want to listen, did not want to burden others, be seen as complaining, or met with attempts to help gain a diagnosis or find a cure (Green et al., 2004; Lempp, Hatch, Carville & Choy, 2009; Nettleton 2006; Nettleton et al., 2004; Nettleton et al., 2005; Toye & Barker, 2010).

Green et al. (2004) reported no participants mentioned stigma, and only one participant said her friends had rejected her, but many had withdrawn themselves from social contact, a finding reflected in accounts across studies reviewed. Experiences of shame and embarrassment were described, including failure completing activities or dependence on others (Nettleton, 2006). Many experienced social isolation, reductions in activity and a loss of self-confidence (Lempp et al., 2009).

1.12.3 Experience of healthcare.

Experiences of healthcare were generally negative, although there were some supportive medical professionals within a difficult healthcare system (Lempp et al., 2009).

Individuals experienced the healthcare system and medical professionals as not understanding, dismissive and having unhelpful attitudes (Arroll & Senior, 2008; Lempp et al., 2009). Some felt that doctors believed they were ‘putting it on’ a ‘fraud’, a ‘time waster’ or inferred a sense of attention seeking (Green et al., 2004; Nettleton et al., 2004). Some reported medical scepticism, and found this damaging and dispiriting (May, Rose & Johnstone, 2000). Expectations of services were not met, with a lack of medical contact and effective treatment reported (Lempp et al., 2009). Some experienced feeling marginalised and excluded from medicine and medical services (Nettleton et al., 2005).

1.12.4 Struggles for legitimacy.

Many experienced fears of the reality of their symptoms being questioned, with concern symptoms are seen as ‘all in the mind’ (Glenton, 2003; Nettleton et al., 2005). Some participants began to question their legitimacy, wondering if they were imagining it, and experiencing a loss of credibility (Toye & Barker, 2010).

Nettleton et al. (2004) argue that participants often did not accept these ideas themselves but without a clear explanation, the discursive resources available to them are very limited. Those remaining may be psychological explanations, which are sometimes considered less legitimate.

The struggle for a diagnosis and failure at this led to feelings of disempowerment (Arroll & Senior, 2008). The inability to achieve a sick role led to some describing feelings of worthlessness (Glenton, 2003). This may be

exacerbated by symptoms, suffering often being invisible, or attempts to conceal symptoms (Lempp et al., 2009). Nettleton (2006) suggests participants felt strongly about having their symptoms acknowledged as genuine by health professionals but also family and friends, and feeling unworthy of help and support without these.

1.12.5 Summary and critique of literature.

In summary, a review of the literature exploring individuals' experiences of MUS has highlighted a number of commonalities in experience. This suggests difficult healthcare experiences, confusion, uncertainty, and struggles for legitimacy may be important in understanding experiences of adults with MUS. Research included a range of symptoms both within and across studies, with all sharing the commonality of lacking a full medical explanation.

Data reviewed were obtained from published peer-reviewed research articles, with original accounts interpreted by researchers using a variety of means. It is acknowledged that this review may not be a full representation of original accounts. Nevertheless, all studies described methods of analysis transparently and provided direct quotations from interviews to provide context and illustrate findings. Therefore these are assumed to provide important representations of accounts of experiences given by adults with MUS.

1.12.6 Family experiences.

The experiences of young people are different to adults due to young people's context and developmental factors, but are not well understood in the literature (Gilleland, Suveg, Jacob & Thomassin, 2009). Despite searching published literature, no research exploring the individual experiences of children with MUS was found.

However, Carter (2002) explored the experiences of three young people with chronic pain and their families, focusing on the role of professionals as they argued this emerged as important from data collected. The pain experienced could have any cause, including a full medical explanation. All families reported numerous encounters with a range of professionals, in a struggle they named the “quest for diagnosis” (Carter, 2002, p28). From their experiences, families were identified to have felt judged, disbelieved and labelled as difficult, contributing to the stress already experienced. They faced difficulty when doctors were unable to provide a diagnosis, identifying a cycle of referrals, building hope then hopelessness, and saw diagnosis as the first step towards treatment.

However, these findings focus on the family experience as a whole and do not provide insight into the representativeness of these perspectives and experiences across different family members or the children themselves. Carter (2002) does however identify that children specifically felt their voices were ignored and their words were misinterpreted and translated through professionals’ perspectives, an experience shared with other family members.

Carter (2002) recommends professionals must base interventions upon a combination of their clinical expertise and an appreciation of the child’s experiences and perspectives.

Adults report experiences of relatives or friends becoming involved in seeking diagnoses, noticing symptoms or pursuing new treatments (Nettleton, 2006). Children with MUS may share similar experiences, especially due to the caring role of parents. However this may be experienced differently as occurring within expected roles, and within a different context.

1.13 Making Sense of Medically Unexplained Symptoms

Individuals' and families' beliefs about symptoms affect symptom experience and management (Pennebaker, 1982). Understanding individuals' perspectives and explanations for their symptoms are essential to facilitate constructing shared understandings and develop effective patient-centred support (Nettleton et al., 2005).

1.13.1 How professionals make sense of medically unexplained symptoms.

Stone (2013b) reported that GPs experience difficulty making sense of MUS, but feel a pressure to support families in the best way they can. Having a label for suffering was seen as important, with the absence of a name described as 'disorientating' or 'anxiety producing'. A name was seen as giving patients' a structure and framework for their suffering and validating symptoms and experience. Labels give a language to make sense of symptoms, and without this a shared narrative had to be carefully constructed. This seemed to be mirrored by patients and doctors. Themes of feeling protective of patients, and treating them with respect while navigating difficult ethical frameworks were identified.

Participants interviewed included early career GPs and supervisors, which provided a range of experiences. However, the assumptions or reflections of the author are unclear. The author is an experienced GP, and this impact on the dynamic in interviews is not discussed. The extent to which the theory was supported across interviews is also unclear.

1.13.2 How adult patients make sense of medically unexplained symptoms.

Nettleton et al. (2004) suggest illness narratives of adults with MUS are chaotic, with no clear beginning or end. They suggest where symptoms cannot be labelled and given a full medical explanation, individuals have no language or medical theory to engage with, causing difficulty making sense of symptoms or constructing explanatory narratives. When medical explanations are excluded, those left are often psychological, which may question legitimacy of symptoms.

The study is clearly presented and a range of experiences and stories are reflected in the analysis and considered within the socio-cultural and ideological context. Two narratives are presented in detail to demonstrate the ideas identified by analysis. However, these stories are structured in a coherent way and fail to demonstrate the lack of coherent narrative and story expressed by the participants.

Nunes, Ventura, Encarnacao, Pinto and Santos (2013) explored patients' explanations of their MUS, and experiences of therapeutic approaches six months after diagnosis. They suggest that patients were able to identify psychosocial causes with the support of doctors, including those who initially reported a biophysical explanation. Patients valued clinicians listening and maintaining flexibility as they progressed through developing an understanding of their symptoms. Interestingly, although patients did not expect medication, this was most often used as treatment, highlighting the mismatch of explanations and expectations between patients and doctors.

A strength of this study was that patients were interviewed six months after diagnosis, enabling the description of progression and development over

time. However two interviews were discarded as patients also had medically explained symptoms and found symptoms difficult to differentiate. This suggests not all patients are able to make sense of their symptoms, but stories that did not fit with the authors' argument were discounted. There is a lack of transparency in the reporting of this research, resulting in difficulties critically evaluating the research and findings.

Soderlund and Malterud (2005) used semi-structured interviews with women with medically unexplained fatigue. They report participants make sense of MUS through a story of pressure in work and family life, emotional conflicts and depleted resources, interacting with a trigger encountering their fragile immune system. This suggests a linear story with a clear explanation. However, some participants expressed difficulty making sense of their symptoms. The authors report they constructed the study and viewed data from a feminist perspective. Therefore the narrow perspective may have led to some stories not being told.

Dwamena, Lyles, Frankel and Smith (2009) used semi-structured interviews. They suggested those showing more psychological insight had less disability and a desire to find an explanation for their symptoms. This contrasted with those who were anxious an illness had been missed, or those with less psychological insight. They highlight some patients described having a diagnosis provided relief. However, it is unclear how level of psychological insight was identified, and labels used seem judgemental and introduce concerns about assumptions applied to data and analysis. Reporting of the study lacks transparency, making critical evaluation of the research and findings difficult.

Green et al. (2004) conducted interviews and highlighted patients' confusion about their symptoms, what to call them and its cause as important. This resulted in difficulty expressing clear ideas about illness time-line, control or cure. They identified a tendency to categorise illness as organic or psychological. Dissatisfaction with doctors when ideas about their symptoms did not match is also described.

Interestingly, patients with MUS may use different descriptions and perspectives when interacting in different settings, with all playing an important role in creating meaning in daily life (Risor, 2009). Participants largely used symptomatic explanations in medical consultations as it was seen as expected. However in everyday life, explanations incorporated personal characteristics, the dominant way of explaining MUS and trying to add meaning and coherence.

Patients described hinting at alternative explanations, such as social factors to the doctors but believed these were dismissed. Therefore, they reverted to a symptomatic, explanation-seeking framework to seek legitimacy and feel heard (Risor, 2009).

Making sense of MUS is very difficult for those who receive a medical diagnosis that is retracted. Katerud, Knizak and Nakken (2010) describe the experiences of ten patients diagnosed with epilepsy and treated with medication who subsequently had the epilepsy diagnosis replaced with a label of non-epileptic seizures. They found when the cause of seizures was unclear, patients described the need to re-evaluate their self-understanding, feelings of hopelessness and helplessness and increased stress. They viewed responsibility as being transferred from health services to themselves. As a whole, they had

difficulties making sense of their symptoms with this new label and having their previous understanding removed.

1.13.3 How families make sense of medically unexplained symptoms.

Morris and Ogden (2012) interviewed mothers of children with MUS and found all mothers tried to make sense of symptoms. Mothers searched for causal models and an illness identity. Many attributed symptoms to a biomedical cause, locating symptoms external to the family, out of control of themselves and defending against any suggestion symptoms may not be authentic. They described symptoms as causing distress and disrupting work and family life. Strategies for coping included normalising or reinforcing symptoms to facilitate a protective relationship with their child.

However, the extent to which perspectives are discussed and shared with children is not considered. Reporting of analysis is unclear, with no discussion of attempts to increase trustworthiness. The researchers discuss associations, but the evidence for these is unclear. Therefore it is difficult to evaluate the quality of these findings, or the relevance to children and their experiences and understanding.

No research was found on children's perspectives of MUS, suggesting the stories and perspectives of children and young people are not held in the research literature. This is an important gap, with understanding of how young people make sense of their MUS essential for effective assessment, engagement in services and developing therapeutic relationships.

1.14 Young People with Chronic Fatigue Syndrome

Despite being a recognised diagnosis, controversy and a lack of clarity, including around aetiology surrounds chronic fatigue syndrome (CFS; Jelbert, Stedman &

Stevens, 2010). Young people with CFS often experience a period of diagnostic uncertainty and barriers to accessing effective treatment (Webb et al., 2011). Therefore, although individuals with CFS are given a diagnosis, there may be some similarities in experience or sense-making processes, suggesting consideration of literature exploring the experiences and perspectives of young people with CFS may be valuable.

Research exploring the experiences of young people with CFS suggest they often experienced difficulty with medical and psychiatric services, including feeling dismissed, not listened to, feeling the reality of their symptoms was questioned, and experiencing a period of diagnostic uncertainty (Hareide, Finset & Wyller, 2011; Jelbert et al., 2010; Richards, Chaplin, Starkey & Turk, 2006; Webb et al., 2011). One study interviewed adolescents in recovery from CFS and identified a theme of loss within their accounts; personal and academic loss and social isolation, although this improved with receipt of a diagnosis and effective intervention (Jelbert et al., 2010). Webb et al. (2011) found similar experiences for parents, in addition to feeling blamed for their child's difficulties and having difficulty communicating to professionals the experiences and symptoms of their child.

Exploration of young peoples' illness beliefs regarding their symptoms suggested most participants were able to make sense of their symptoms by attributing an organic aetiology, usually with an infection identified as a trigger (Hareide et al., 2011; Jelbert et al., 2010; Richards et al., 2006; Webb et al., 2011). Only one study describes any participants considering the impact of psychosocial factors in the development and maintenance of their symptoms, and this was only a minority of participants (Hareide et al., 2011). These studies

generally explored illness beliefs using qualitative research, with some mixed methods used, and aimed for in-depth exploration of perspectives and experiences. However reporting often lacks transparency, and although themes identified are presented alongside data extracts, the development of themes and relation of these to accounts is difficult to conceptualise. It is unclear from the research how participants have developed these understandings of their illness, and any exploration of sense-making or consistency in explanation is limited.

1.15 Research Methods

Research exploring how people experience and make sense of MUS has been conducted using both quantitative and qualitative methodology. Both methodologies have advantages and disadvantages. Quantitative methodology allows statistical analysis and comparison of groups, often investigating hypotheses (Field, 2005). However, this requires enough previous research and literature to develop meaningful hypotheses for testing. It also restricts general exploration.

In contrast, qualitative research encourages exploration and discussion with participants to explore individual experiences, perspectives and accounts. This enables the development of future research, which may include the development of hypotheses to be tested.

Charmaz (2008) discusses how people with chronic illness, especially MUS are marginalised, particularly within the medical services. Charmaz (2008) aligns this with the marginalisation of qualitative research, drawing comparisons between struggles for legitimacy, lack of understanding and experience in MUS.

Research reviewed throughout this introduction has highlighted differences in parent and child report of the same situation, symptoms or

experience. Therefore, research needs to collect data from children to reflect their perceptions, symptoms and experiences (Weisblatt et al., 2011).

However, it can be difficult to represent children and young people in research. For children under the age of 16, parents decide participation in research. Participation by those aged 16-17 may be decided by the young person, but this is strongly influenced by parents, who may be the original point of contact for researchers approaching the family (Eminson, 2007). Research using children and young people is also dependent on the availability and use of valid, appropriate assessment measures and data collection methods, which are designed for the verbal, cognitive and emotional development of those studied (Weisblatt et al., 2011). In a review of the area, Eminson (2007) concluded that interviewers asking about a young person's experience and framing their questions appropriately, with account of development can gain reliable answers from young people. Therefore, developmentally appropriate interviews may be an appropriate method when exploring the experience of young people with MUS.

1.16 Summary and Rationale for Research

In summary, MUS are a significant problem for families and the healthcare system. MUS are poorly understood and this is reflected by the confusing use of different names, labels and language. Symptoms are medically unexplained, but how this uncertainty around explanation is managed is unclear. People with MUS struggle for legitimacy and feel disempowered (Stone, 2013a).

Professionals are struggling to make sense of symptoms, and research focusing on this explores a wide range of possible models with new ideas being developed. The breadth of models, theories and perspectives proposed is wide-

ranging, making the field baffling and rendering evidence-based practice and development of clinical guidelines very difficult.

However, research and guidelines discussed suggest the most important factor for therapeutic engagement is building a shared narrative of the symptoms. Therefore, regardless of the explanation of symptoms or intervention adopted by professionals, it is essential to understand the experience and perspectives of the patient. Some research exploring the experiences and perspectives of adults with MUS is emerging and can inform clinical practice. However, the experiences and perspectives of children and young people with MUS are not held in the literature. Exploration of these experiences and perspectives is important due to the differences in experiences, opportunities, identity formation and life transitions young people will be experiencing. This is essential to enable this joint construction of a shared narrative, empowerment of the individual and build engagement with services.

1.17 Aims and Research Questions

The aim of the proposed study is therefore to explore young people's experience of their MUS and the way they make sense of and attach meaning to these symptoms. The current study is exploratory and concerned with participant perspectives, thus a qualitative methodology is most appropriate, as it allows for an investigation into the quality and content of experiences (Willig, 2001).

Research questions aim to capture a wide range of experiences and perspectives, whilst acknowledging, "qualitative approaches usually entail formulating questions to be explored and developed in the research process, rather than hypotheses to be tested by or against empirical research" (Mason,

1996, p. 15). This study therefore aims to explore the following research questions:

1. How do young people experience MUS?
2. How do they make sense of their symptoms?

Method

2.1 Summary

This chapter describes the research design, procedure and the process of data analysis. Methodological rigour and ethical considerations are also discussed.

2.2 Qualitative Framework

Qualitative research is conducted to understand more about a phenomenon, often by exploring the perspectives and experiences of those within the particular population, or with the specific characteristics or experiences being explored (Green & Thorogood, 2014). A qualitative design enables investigation into the quality and content of perspectives (Willig, 2013). This study is explorative and aims to explore individual experiences and perspectives and thus a qualitative design is appropriate. As discussed in the introduction chapter, it is important to explore the experiences and understandings of young people with MUS. A qualitative framework and the flexible, exploratory nature of this is considered more likely to generate a fuller representation and account of participants' experiences and perspectives than a structured quantitative approach (Green & Thorogood, 2014).

2.2.1 Ontological and epistemological position.

Assumptions made about the nature of reality and the nature of knowledge impact on all stages of the research process, from design to how data are approached (Willig, 2000). Therefore, as recommended by Mason (2002) the

ontological and epistemological positions and assumptions underpinning the current research are clarified.

Ontology relates to ideas around the nature of being, including assumptions around the relationship between reality and human interpretations and practices; determining whether we think reality exists separate from humans, practices and understandings (Flick, 2014). Epistemology is concerned with the study of knowledge and assumptions around the nature, scope and limitations of knowledge (Flick, 2014). Therefore, ontology and epistemology are often intertwined and determine constraints for appropriate research methodologies.

A ‘critical realist’ perspective was adopted for the research, located between the realist and constructionist positions. This assumes there is a reality that exists independent of human interactions and practices, but we may not be able to access this fully (Flick, 2014). This approach acknowledges that people construct meanings from their perspectives, assumes people discuss views and perspectives that are true for them, have some meaning attached to this truth, and considers the broader social context while acknowledging the limits of reality (Braun & Clarke, 2006).

This perspective also acknowledges the impact of the researcher’s subjective influence on the research (Willig, 2001), and aims to acknowledge and reduce this influence by increasing trustworthiness. It is therefore assumed that there is a social world that exists independently of the individuals’ subjective experience but that we access this through the interpretations of both the participant and the researcher. Therefore the researcher’s position and assumptions are reported throughout to provide transparency and enhance the quality of the research.

The critical realist position has been taken rather than constructionist, because as discussed in the introduction, many people experiencing MUS do not feel believed, listened to or understood by others. It was felt to be important that their stories were listened to, and accounts understood as people telling their true stories, rather than understanding their accounts as having different meaning and existing only as created within that interaction.

In addition, assumptions about children and young people and the use of children in research were considered as recommended by Greig, Taylor and MacKay (2007). Reflection identified these as valuing the experiences of young people and their stories, and the importance of documenting their stories in the literature to enable learning from these. These assumptions and values fit with the critical realist perspective; recognising the value of documenting stories that are the truth for young people but recognising the limits of the situation. It is unlikely the full truth and experiences of young people will be reflected in any amount of data collection, with a single interview allowing a glimpse of this.

2.3 Participants

Sampling in qualitative research aims to explore the insider perspective of people in detail to provide an in-depth representation rather than achieving statistical generalisability (Willig, 2013). Therefore, sampling aimed to achieve exploration of the experiences and perspectives of a small sample of young people experiencing symptoms that they have been told do not have a full medical explanation, whilst allowing investigation of experiences across multiple participants.

2.3.1 Inclusion and exclusion criteria.

Young people included were experiencing symptoms which were considered to not have a full medical explanation, or symptoms above and beyond those explained by any medical diagnosis. To be included, a medical professional must have communicated to the young person and family that there is no full medical explanation for their symptoms, to ensure any medical cause for symptoms has been investigated and excluded. Inclusion and exclusion criteria are detailed in Table 1.

Table 1. *Participant Inclusion and Exclusion Criteria*

Inclusion	Exclusion
Aged 11-17 years	Having ongoing medical investigations for symptoms on the advice of professionals
Minimum symptom duration of 6 months	Communication or learning difficulties to the extent could not engage in an interview
Symptoms they have been told are MUS, may include an additional medical condition	Would be distressed by an interview

2.3.2 Potential participants.

Purposive sampling was used, aiming to recruit participants with the experiences necessary to explore topics related to the research questions (Flick, 2014). All families identified as meeting the specified inclusion and exclusion criteria by the clinical psychologists involved were given research information sheets. In

total, 19 potential participants were approached and received research information sheets.

2.3.3 Sampling.

It can be difficult to determine sample size in qualitative research, with sample size dependent on numerous factors, including internal factors such as epistemological position, type of analysis and external factors such as time, resources and satisfying necessary review and funding bodies (Baker & Edwards, 2012). One approach cited as ideal is aiming to attempt data saturation, where no new themes are developed from new interviews (Mason, 1996). However, this is an approach used more with other methods of analysis, such as grounded theory. The current research aims to explore a range of perspectives and experiences but does not attempt to represent all possible experiences and perspectives of this group. In addition, this would involve analysis alongside data collection, which may generate assumptions about the content of future interviews and reduce researcher flexibility. Instead, a more linear process was used with analysis following data collection and transcription.

Following recommendations from Guest, Bruce and Johnson (2006), it was planned to review data collected after six interviews against the sampling aim. It was assumed interviews with young people could be shorter or lacking in relevant content. Data collected after six interviews were reviewed against the sampling aim to achieve in-depth exploration of the experiences and perspectives of a small sample of young people experiencing MUS, whilst allowing investigation of experiences across multiple participants (Baker & Edwards, 2012). This review suggested more data than expected had been collected during

these interviews. Following this, interview data were reviewed alongside sampling aims following each interview, with consideration of time constraints. This resulted in data collection finishing after nine participants. A description of each participant is presented in the results chapter, section 3.1.

2.4 Procedure

2.4.1 Making contact with participants.

Participants were recruited from two hospital sites. Clinicians including paediatricians, nurses and psychologists were made aware of the research and provided with research information packs to distribute to families meeting the research inclusion criteria. Dependent on families' preferences, they could contact the researcher directly to ask questions or give consent or complete and return a consent to contact form. Two parents contacted the researcher directly and seven participants and their parents gave the contacting psychologist permission to provide the researcher with their details to make contact.

2.4.2 Data collection.

Data collection consisted of a contextual information questionnaire completed by a parent/carer and a semi-structured interview with the young person.

2.4.2.1 Contextual questionnaire.

A questionnaire was developed for the research to be completed by a parent/carer during the interview. This aimed to gather data to put accounts from interviews into context, with questions asking about symptoms, duration, investigations and functional impact of symptoms, for example on school attendance. In all cases, mothers chose to complete the questionnaire, and so it is acknowledged this will only reflect the mothers' perspectives. A copy of the questionnaire can be found in Appendix A.

2.4.2.2 Semi-structured interviews.

Semi-structured interviews are widely used in qualitative research due to the view that flexible interview situations are more likely to elicit participants' viewpoints than a structured situation (Flick, 2014). Interviews are most useful when exploring experiences and perspectives of people who may be difficult to engage in research due to the flexibility this offers, including in location and time of the interview and the ability to tailor the interview to their individual communication needs (Flick, 2014).

A semi-structured format enabled participants to share their experiences whilst providing a loose structure aimed at exploring the research questions. Interviews are useful when examining sense-making, and where narratives may involve contradiction, complexity or ambiguity (Brannen, 2005). According to Green and Thorogood (2014), semi-structured interviews are particularly useful when exploring illness experiences and narratives.

The use of focus groups was considered as an alternative means of data collection. However, Wills (2010) suggest young people and particularly adolescents may find focus groups intimidating or be concerned about confidentiality, resulting in limited data, which are unlikely to reflect their true experiences and perspectives.

2.4.2.3 Interview guide.

An interview guide was used to guide the interviewer and interviewee, and applied flexibly to give space to the interviewee's perspective and additional topics that may arise (Braun & Clarke, 2014). The interview guide is presented in Appendix B. Although the researcher identified topics to guide the discussion, interviewee's responses determined the relative importance of each topic and the

information produced about each topic (Green & Thorogood, 2014). Flexible use of the interview guide allowed the process and conversations to be steered by participants as much as possible, allowing participants' accounts to be told in a way that was meaningful for them (Chiviotti & Piran, 2003).

Interviews were intended to be responsive, with emphasis on the importance of building a rapport in the interview leading to a more balanced conversation (Rubin & Rubin, 2012). A friendly and gentle tone of questioning was adopted with the researcher aiming to facilitate rapport building and for the young people to offer full accounts of their perspective. Sensitivity was used when deciding when to probe further about a topic or part of a story.

Participants' own language and everyday language was used as much as possible as interviews aimed to explore the life world of the participant, not theoretical concepts. This was particularly important for describing their symptoms, using the explanations and language they used rather than providing possible labels or explanations the researcher held. Use of participants' language is argued to be particularly important in research with young people in ensuring understanding and building trust and rapport (Greig et al., 2007).

The interview guide was developed following reviews of relevant literature and discussions with research supervisors, clinicians working in the field and discussion at the Qualitative Research Forum at the University of East Anglia (UEA). The guide was designed to include topics relating to the proposed research questions. All interviews began with broad questions, progressing to more specific sensitive questions, such as asking how they would explain their symptoms to someone. The funnelling technique described by Richard and Whyte (2008) was applied, creating a structure whereby open questions are

followed by a series of prompt questions, particularly to help explore the response, for clarification or if the open question was misinterpreted.

The interview guide was further developed through an iterative process of initial interviews and participant feedback. Transcripts of the first two interviews were reviewed by the researcher and research supervisor to evaluate and adapt the existing interview schedule. This was used to inform the interview guide used for subsequent interviews, for example it was agreed to focus more on building a comprehensive picture of the symptoms experienced towards the beginning of the interview.

All interviews ended with the opportunity for the participant to add anything and participants were asked to provide feedback from the interview and suggestions for further questions. This was to ensure topics important to them had been discussed and also provided some feedback regarding the topic schedule for future interviews. Finally participants were told how to contact the researcher later if they had any questions or wanted to withdraw from the research prior to data analysis.

2.4.2.4 Conducting interviews.

Interviewing of young people and data collected from these can make an important contribution to qualitative research but extra considerations are needed to ensure interviews are comfortable and young people can express their own ideas (Scott, 2008). Interviews were conducted at the clinic the young person usually attends or at home depending on their preference.

One participant chose to have the interview in clinic, and eight participants chose to have the interview at home. The UEA lone working policy was followed for all visits, including visits during working hours and use of a

buddy system. Interviews were audio-recorded using a digital voice recorder. Participants' level of engagement was monitored alongside interview length to reduce demand. Interview lengths ranged from 47 minutes to 109 minutes, with the average interview time 68 minutes. Time was allowed at the start for building participant engagement through talking about things the participant was interested in or playing an age-appropriate game on an iPad. However, all participants were keen to begin the interview when given a choice. Participants were given a £10 'one 4 all' voucher to thank them for giving their time to participate.

Reflective notes were made prior to the interview, considering the researcher's assumptions about the participants, assumptions for the interview, concerns and areas of interest for conversations within the interview. Reflective notes on the experience of the interview and the impact of the assumptions noted prior to the interview were made within one hour following completion of interviews.

2.5 Data analysis

2.5.1 Thematic analysis.

Thematic analysis can be defined as a “method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 6), allowing the researcher to analyse and interpret data. Thematic analysis is a method of analysis that can be used flexibly across a range of methods of data collection, ontological, theoretical and epistemological positions (Braun & Clarke, 2013). As a method, thematic analysis has a number of advantages. It is considered an appropriate method for early-stage qualitative researchers, can provide a rich account of data, enables the development of new insights and perspectives from

the data and allows patterns and similarities and differences across data to be highlighted (Braun & Clarke, 2006).

Qualitative research is often criticised due to the lack of clarity and clear guidelines for methods, resulting in difficulties evaluating and extending research (Antaki, Billig, Edwards & Potter, 2002). However in response to this criticism, guidelines for thematic analysis have been published and clearly outline processes and increase trustworthiness of the research (Braun & Clarke, 2006). This research follows the approach proposed by Braun and Clarke (2006) and their guidelines for conducting rigorous thematic analysis.

It is possible to use thematic analysis to provide a description of themes across the dataset or a more detailed account of one or few themes identified. Themes can be identified using an inductive, data-driven approach, or using a deductive theoretical-driven approach. An inductive approach was adopted with themes identified generated from interview data rather than being theoretically driven (Patton, 1990).

2.5.1.1 Transcription and familiarisation.

Recordings were transcribed by the researcher and the transcription reviewed against the recording for accuracy. Transcriptions included a verbatim account of all words used in the interview. It is acknowledged that despite endeavours to ensure verbatim account of interviews, transcription of verbal utterances cannot capture non-verbal aspects of communication and as such it is not a complete account (Mason, 2002). However, the level of transcription is appropriate for the method of analysis and critical realist position (Braun & Clarke, 2013).

Researcher observations, interpretations and experiences were recorded and reviewed alongside transcripts to support interpretation. Immersion in the

data was aimed for; involving transcription of interview recordings, repeated readings of transcripts whilst listening to the recordings, including reading while searching for patterns (Braun & Clarke, 2006).

2.5.1.2 Thematic analysis process.

Thematic analysis was conducted following the guidelines and processes outlined in Braun and Clarke (2006). Following data transcription and familiarisation, the following processes were completed in analysis.

Initial codes to identify content or meaning were generated from the data using an inductive approach. Coding aimed to stay very close to participants' words to ensure coding was completed without significant impact from the researcher. Therefore, in total, 2716 codes were generated. When appropriate multiple codes were generated for segments of data. Electronic data management software (QSR NVivo 10 for Macintosh) was used to facilitate the coding process; allowing electronic codes to be generated and assigned and coded data extracts to be collated in electronic files. An extract of a transcript annotated with codes is provided as an example in appendix C. Coding was discussed in research supervision, with some shared coding of extracts.

Following coding of the dataset, codes were reviewed multiple times at different stages of analysis. Codes with the same meaning were merged into one code. Similar codes were grouped together, and ordered in a hierarchy within that group. A miscellaneous group of codes was generated, and singular codes that could not be grouped with other codes were moved into this. As analysis progressed, groups of codes were repeatedly added to, combined and more codes assigned to the miscellaneous code. This process was repeated continually with groups of codes becoming larger, and smaller groups that were decided to not

reflect the dataset, or be relevant to other groups of codes or participants were assigned to the miscellaneous code. This continued until there were large groups of codes, organised in hierarchies within codes. Grouping of codes was reviewed frequently in research supervision. Codes within the miscellaneous group were reviewed and any that fit within the groups of codes were moved into this group. The internal homogeneity of groups of codes was reviewed and any codes or groups of codes that did not fit were considered for moving elsewhere or moved into the miscellaneous group.

Groups of codes were organised into a visual diagram to facilitate the consideration of links between codes and collating codes to identify themes. Different combinations and organisations were considered and reviewed alongside the data. Research supervision enabled reflections and consideration of alternative combinations. Any evidence that did not support the grouping of codes, or cases that did not fit were searched for. Remaining groups of codes were combined to form overarching themes. Identified themes were considered in terms of prevalence across and within accounts.

The structure of sub-themes within themes was considered and identified themes were refined. Themes were reviewed in conjunction with the data to consider the strength of evidence for themes identified and overlaps between themes. Criteria for internal homogeneity, where data within themes should fit together meaningfully and external homogeneity, where there should be a clear identifiable distinction between themes (Patton, 1990) were applied when reviewing themes. A thematic map was constructed and reviewed to determine whether the map and themes contained a representation of the interviews.

Additional coded data were added into themes as necessary. The thematic map was reviewed and adjusted as part of the on-going process.

Following the completion of the thematic map considered to represent the interviews, themes were defined and further refined. Transcripts were reviewed alongside themes as another stage to ensure themes represented data collected. Collated data extracts for each theme were organised into a coherent account and themes considered in relation to each other, research questions and the entire dataset. Themes and sub-themes were named, with names reviewed and adjusted throughout the process.

Discussions within research supervision were used throughout the process, with coding, grouping of codes, organisation of groups of codes, potential themes, sub-themes and visual representations of these reviewed and refined. Explaining the themes and sub-themes to another also highlighted any discrepancies, and enabled discussion and reflection on whether the names of the themes reflected the content in a meaningful way.

2.6 Methodological Rigour

It is important for research to provide clarity around assumptions, processes and methods to allow evaluation, compare and synthesise with similar research and allow researchers to conduct related projects (Attride-Stirling, 2001). Quality of qualitative research can be critically evaluated through examination of methodological rigour. Koch (2006) argues that rigour, often referred to as trustworthiness can be established if the reader can establish a comprehensive audit of the events and actions of the researcher and influences of the researcher. A variety of different criteria and frameworks have been suggested (Tracy, 2010). Generally regarded quality markers of quantitative research, such as

reliability, generalisability and objectivity, do not directly translate to the aims and methods of qualitative research (Guba & Lincoln, 2005).

Elliott, Fischer and Rennie (1999) describe:

The aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage, and live through situations . . . the researcher attempts to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied (p. 216).

This aim is shared by this research, and so quality criteria proposed by Elliot et al. (1999) are considered in addition to more recently published criteria. Issues of trustworthiness and rigour were considered throughout this research, with considerations discussed below.

2.6.1 Researcher's perspective.

A fundamental component of good qualitative research is for researchers to acknowledge and state their values, expectations and assumptions, in what Elliot et al. (1999) describe as owning one's perspective. As described above, a critical realist position has been adopted in this research. This values the accounts of others, their experiences and how they talk about these but also recognises the researcher will have some impact on these and we are unlikely to discover the whole truth for a participant. As this section describes the researcher's perspective about the development of the research and the impact of their experiences on this, the following section is written using the first person.

2.6.1.1 Development of the research.

The idea for this research was developed over the course of many months and in consultation with psychologists working with young people with MUS.

Originally I had considered a quantitative exploration, but the large sample size required felt like a barrier. I returned to the literature and discovered that despite many articles purporting factors contributing to MUS or interventions for MUS, found very little exploring the perspectives and experiences of people with these symptoms. I was surprised their perspectives and experiences were not represented when this felt so important, but it seemed like a perfect opportunity to explore this. A fuller reflective statement is located in Appendix D.

Inevitably, external constraints have affected the research. For example, this project is completed as part of a doctorate in clinical psychology and as such is expected to be doctoral-level research. It must be completed within a limited timescale and completed and written in a way to meet the expectations of examiners. I felt particularly pressurised by time limitations and wonder if this perhaps made my approach rather pragmatic. In addition, research supervisors have valuable knowledge and experience and shape the way the project has been developed, completed and written.

2.6.1.2 Researcher's reflections on experiences contributing to the research.

A full account of these reflections is located in Appendix E. I am a 27-year-old female white British trainee clinical psychologist. I have always lived in England, except for 6 months when I lived in South-East Asia. I believe my previous work experience in addition to my time in South-East Asia has contributed towards the research, and development of my experiences and assumptions. One example would be the value of acceptance and living with uncertainty achieved in South-East Asia which seemed so different to my experiences.

When working with young people with MUS, I struggled to make sense of their symptoms, which seemed exacerbated by lacking language to talk about these symptoms. I wonder about the impact of this on the way people make sense of their symptoms. This was a real challenge and resulted in my having questions regarding how young people can talk about and make sense of their symptoms.

These experiences and reflections have informed the ideas behind the research, the design, research questions and method of data collection. I am now in a position where I hope to be able to explore these. I have also developed assumptions about ideas or topics that may be important and am aware these may impact on data analysis. I assume that there must be uncertainty that is difficult to manage. I assume that young people will have difficulty making sense of their symptoms, and I am curious about how they have managed to do this, and to what extent and what factors or people in their system have contributed to this. Transparently reporting my assumptions and reflecting on the impact of these throughout the research process will improve the rigour of this research.

2.6.2 Situating the sample.

The sample is not intended to be representative of all young people with MUS. Instead it represents a range of experiences and remains true to these experiences and perspectives whilst looking within and across accounts for similarities and differences to build our understanding. It is hoped this research may contribute to clinical understanding.

According to Elliott et al. (1999) it is important to situate the sample to allow consideration of potential relevance of findings. As previously discussed, information has been collected to provide context to the data and analysis, and is used to build a description of each participant, reported in the results chapter.

2.6.3 Transparency and coherence.

Following recommendations by Elliot et al. (1999) the research intended to present a coherent story derived from the data, which is based in the data and represents the researcher's understanding. Although the research aims to remain true to participants' accounts, inevitably, the researcher will be positioned within this and may in some ways shape the stories told. Therefore, it is important for the researcher to be transparent about the research process and their own assumptions and values and the impact of these (Elliot et al., 1999). It is intended for the research to be presented transparently at all stages of the research process.

Explicitly, this study aimed to use thematic analysis of semi-structured interviews to provide a coherent story to explore and represent how young people with MUS experience and make sense of their symptoms. The research had a focus on young peoples' perspectives with the objective of representing a range of experiences to consider clinical implications and to develop further research.

Following recommendations by Tracy (2010), the current research uses methods and procedures suitable for the research questions and research goals and interconnects literature and research questions throughout to achieve meaningful coherence. Justifications for research decisions are interwoven throughout the report. For example, the decision to use qualitative methodology, interviews and epistemological position adopted are discussed within this chapter.

Particular consideration has been given to transparency in the presentation and analysis of data to help achieve coherence. To facilitate this, all themes presented are grounded in data examples and extracts from the

researchers' reflective journal added into the discussion chapter to illustrate the assumptions and values impacting on the analytical process. A sample interview transcript extract is provided in the appendix to allow further consideration of themes in context of the data.

2.6.4 Commitment and rigour.

In addition, Yardley (2000) highlights the importance of commitment, defined by engagement with the topic and rigour in the completeness of data collection and analysis. Throughout the research process, relevant literature was searched for and engaged with and data immersion aimed for.

The issue of completeness of data analysis was facilitated through completeness of interpretation, with observed variation, ambiguity and complexity considered. Analysis was inductive, and all data searched, with examination beyond questions asked. Analysis attempted to encompass the range of experiences to present a coherent representation. Codes and themes identified were considered within and across accounts. Themes and codes were reviewed against data to explore instances where they were not appropriate and did not represent the data, and adjusted as necessary (Braun & Clarke, 2013).

The use of triangulation was considered to allow incorporation of an alternative perspective from another researcher or supervisor into analysis. However it is acknowledged that the researcher will interpret the data to an extent through their analysis. Therefore it was more appropriate for analysis to be cross-checked, with feedback provided on coding and themes identified to enable reflection of the researcher about their position and perspectives of the data. Extracts of data, coding and themes in supervision were reviewed with research supervisors. Dr Paul Fisher, the secondary research supervisor, completed this.

Although participant verification was considered, this raised issues around confidentiality, with it difficult to provide participants with copies of their transcripts or initial analysis whilst ensuring this would not be seen by their family members. Young people may meet expectations or pressure to share this with others and this may cause some distress. This threat to privacy may also have affected the accounts participants gave.

2.6.5 Reflexivity.

Smith (2006) argues that credibility and trustworthiness of qualitative data can be improved by increasing reflexivity of research. The value of reflexivity is generally accepted in qualitative research (Ortlipp, 2008). Researchers are encouraged to: talk about themselves, “their presuppositions, choices, experiences, and actions during the research process” (Mruck & Breuer, 2003, p. 3). However, the reflexive component of research is often lost within the report (Smith, 2006). As this research aimed to represent participants’ accounts, reflexivity is particularly important to consider the perspective and assumptions the researcher is bringing to the data and analysis. Section 2.6.1 details reflections by the researcher on the experiences and motivations contributing to the research. Section 2.6.1 also considers external constraints influencing the research. Further reflections are located in Appendices D and E.

Notes were made throughout the research and analysis in the form of a reflective journal to facilitate awareness of how data were being engaged with (Smith, 2006). The reflective journal included process notes, observations and reflections following each interview. These notes were used throughout analysis to support conceptualisation of themes and maintain a focus on reflexivity and engagement with data. Extracts relevant to analysis and experiences of interview

are presented during the discussion of the results and interview experiences, as recommended by Koch, (2006). The inclusion of the journal and extracts aimed to increase transparency (Ortlipp, 2008). However, there is a dilemma between balancing the emphasis of under-represented participants' views and the emphasis on self-reflection and the researcher's perspectives (Smith, 2006). It is assumed the participants may have felt not listened to in the past, so the focus is on participant accounts. Researcher self-reflections are used as an addition.

2.6.6 Impact and importance.

Tracy (2010) suggests good quality research should be relevant, timely, interesting and significant. The current study aimed to explore and report discussions of the clinical implications of this research. Future directions for research are also discussed. The researcher and associated clinicians supporting the research value this area of research, and argue the importance of this research. Explicitly, the researcher hoped this research may impact on the way clinicians and professionals understand, communicate and interact with young people with MUS. Clinical justification of the research including the relevance and timely nature are explored and discussed in the introduction chapter of this thesis. Justifying the impact and importance was an important part of gaining necessary scientific and ethical approvals.

2.7 Ethical Considerations

This study received ethical approval from the Research Ethics Committee and the local Research and Development departments at each site. Documentation is located in Appendices F-H. Prior to submission to the Research Ethics Committee, the project was also reviewed and issues of scientific justification and importance of the research considered and approved by internal review at

UEA and one hospital site. The following ethical issues were considered in designing and conducting the research.

2.7.1 Informed consent.

Following Health Research Authority (HRA) guidance, 11-15 year olds gave assent with parents/carers providing consent and 16-17 year olds provided consent (HRA; 2014). Separate research information sheets (Appendices I-K) and consent forms (Appendices L-N) were provided for parents/carers, 16-17 year olds and 11-15 year olds to ensure information was accessible.

Families were informed of the right to withdraw from the research at any point until data analysis in writing and verbally. The time limit of prior to analysis is necessary as it would be practically very difficult to remove individual data after analysis has commenced. Families were fully informed about plans for dissemination of the research.

Issues of coercion were considered. Families could only participate in the research if both the young person and parent/carer agreed. Research information packs were given to families by clinicians. However, informed consent was taken by the researcher who was external to the clinical team. Families were made aware that any decisions to participate or not in the research would not affect on-going clinical care. All participants were informed that if they began the interview but decided to discontinue, they would still receive a voucher.

2.7.2 Confidentiality and anonymity.

Information regarding confidentiality and anonymity was included in research information sheets for young people and parents/carers and the nature and limits of confidentiality discussed before data collection. Particular time was spent discussing this and checking understanding as adolescent participants may have

particular concerns about privacy and confidentiality (Wills, 2010). It was clarified that although data would be anonymised during transcription, direct quotes would be used in the writing of the research, meaning an individual or others close to them may be able to identify them through their language or ways of talking.

Names of people and places were changed during transcription, and a pseudonym assigned to all participants. All contextual questionnaires completed by parents and interview recordings and transcripts were identified by unique codes. Consent and assent forms containing personal information were stored separately. Any identifying data will be destroyed after assessment of the research. Following submission, data will be retained for five years in accordance with NHS protocol and the Data Protection Act (1998) to allow for critical review. Data will be stored in the research archives at the UEA or at the NHS site it was collected from.

2.7.3 Avoidance of harm.

When people agree to participate in research they enter into a relationship of trust with the researcher and it is the duty of the researcher to ensure participants are not placed at any risk of harm.

2.7.3.1 Participant distress.

Exclusion criteria highlighted that if clinicians believe a participant would be distressed by the interview, they will not be invited to participate. Clinicians have valuable skills in clinical judgment and risk assessment and were encouraged to use these when deciding whether to invite families and young people to participate.

If any participants showed distress during the interview the planned

response was for the researcher to respond by providing some short-term opportunity to discuss the matter appropriately. The interviewer was a trainee clinical psychologist with skills and experience in working with families and young people and containing distress. Should it be required, participants would be encouraged to contact the clinician they are assigned as part of the service they are in, or their GP. If the researcher believed there was a risk of significant harm to the participant or others, they would inform the participant they would need to break confidentiality and inform parents/carers and the clinical team as appropriate. Participant and parent/carer information sheets detail relevant contact information, including of the individual's clinical team and Childline should participants require support later.

2.7.3.2 Misrepresentation.

Qualitative research and data analysis is an interpretative process influenced by cultural, theoretical, personal and epistemological factors and experiences of the researcher (Braun & Clarke, 2013). Therefore there is the potential for participants to feel their experiences and understandings were taken out of context or misrepresented. To reduce this risk, supervision and discussions in the Qualitative Research Forum at the UEA were used to enable the researcher to reflect on personal and theoretical characteristics that may influence the interpretation of data. In addition, the context of interviews was considered important, with recordings and transcriptions being returned to throughout analysis.

Results

This chapter describes the results of the data analysis described in the method chapter. A short description of each participant provides context for the results reported. Three themes and 12 subthemes were developed from the data, and are described within this chapter. Direct quotations from interviews are provided to demonstrate the presence of themes within the data collected. As an inductive approach to analysis was used, although the findings relate to the research questions and provide information to answer these, this section is structured by themes developed from the data rather than by research questions.

3.1 Description of Participants

Information was gathered from parents, and so only provides a parental perspective. In all families, the mother chose to provide the information. Any identifying information, including names, has been changed to maintain confidentiality. All participants are white British. All participants had seen a variety of professionals across different sites and departments, and experienced a number of investigations, often invasive and painful.

Kate is a 13-year-old female experiencing stomach aches, constipation, nausea, headaches, weight loss and fatigue for approximately two years. At the time of the interview she had completed four sessions with a psychologist. Kate is prescribed two types of medication for her symptoms. Kate has missed a substantial amount of school and had to stop her activities and hobbies due to her symptoms. Her mother reported that Kate's symptoms are improving, and that Kate "seems to be slowly returning back to normal".

Lucy is a 15-year-old female experiencing non-epileptic absence and tonic-clonic seizures, loss of vision and use of legs and fainting for

approximately two years. She also has a diagnosis of epilepsy. Lucy is currently receiving psychological support. Her mother described trying to “keep things as normal as possible”, but the mixture of seizures results in all seizures being treated with medication as epileptic seizures and comments from peers at school that she is “faking it”.

Matthew is a 15-year-old male experiencing unexplained seizures, migraines and episodes involving difficulties with coordination, communication and loss of cognitive ability for approximately eight years. He was initially diagnosed with epilepsy and treated with a large dose of sodium valproate for a long period of time. His mother requested a second opinion, and following this, the diagnosis of epilepsy was retracted. He is currently having sessions with a psychologist. His mother reported a previous assessment suggested psychological support was needed, but they were told they could not be provided with the relevant services. Matthew has missed a substantial amount of school and this has affected his performance, and his mother expects this to affect his GCSE results. His mother also described bullying at school and thought it was important for the researcher to know the family broke up around the time the seizures started, with his father leaving, ending their relationship that was abusive.

Natalie is a 14-year-old female experiencing constipation, stomach pain and soiling for approximately three years. She has had a range of investigations, and is prescribed medication. She has received four sessions of psychology. These symptoms stopped Natalie going out with friends and staying round friends' houses. Her mother reported that Natalie has become more confident in herself following this support and is more able to manage her symptoms.

Beth is a 12-year-old female experiencing unexplained seizures, migraines, fatigue, respiratory difficulties and bowel problems for approximately three years. She initially received a diagnosis of epilepsy, which was retracted, then reinstated then retracted again. She was prescribed a range of medication for epilepsy for over two years. Her mother reported the medication was unnecessary and had negative side effects, affecting her cognitive ability and school engagement. Her mother reported that Beth missed a large amount of school, isolated herself, stopped all activities and hobbies and was excluded from school trips and swimming lessons due to the risk of a seizure. She previously had support for managing epilepsy and is currently seeing a psychologist.

Leanne is a 13-year-old female experiencing stomach pain, headaches, sore throat, fatigue and pain in legs and joints for approximately eight years. At the time of the interview, she was waiting for psychology. Leanne has missed a lot of school. Her mother reported Leanne has a diagnosis of eosinophilic enterocolitis but this does not account for the extent of her symptoms. Leanne did not have a clear understanding of this diagnosis. She is prescribed medication to take as needed.

Lauren is a 13-year-old female experiencing stomach pain, difficulties eating and dizziness for approximately a year, although her mother reported the symptoms had improved. She had gastrointestinal ulcers but pain continued after these were treated. Lauren missed a lot of school and stopped all activities due to being unable to walk or travel due to pain. Her mother reported Lauren lost a significant amount of weight over a short period. Lauren had received prescribed medication and two sessions of psychology.

Claire is a 16-year-old female experiencing stomach pain, nausea, bloating and shortness of breath for approximately eleven years. She missed a lot of school and activities. Her mother reported a range of medications have been prescribed over the years but have not worked. Claire is currently engaging in sessions with a psychologist.

Jake is a 13-year-old male experiencing pain in his stomach, ribs, bowel, chest and head, reflux and fatigue for approximately four years. He is currently attending a medical needs school with shortened hours. He has missed a lot of school and stopped all activity. His mother described he has “become very withdrawn”. He has previously seen a psychologist at a Child and Adolescent Mental Health Service, and is currently accessing a service specialising in anxiety and depression support while awaiting psychology sessions with the hospital. His mother reported that Jake’s father had previously been physically abusive to Jake, but they no longer had contact with him.

3.2 Overview of Themes

Three themes and 12 sub-themes were developed from the data using inductive thematic analysis. Figure 1 details these themes and sub-themes. The three themes encompass the difficulty young people had making sense of their symptoms, how hard it is living with these symptoms and how despite challenges, they are trying to get on with their lives. Each sub-theme describes an area encompassed by the theme in more detail. ‘Difficulty making sense’ captures how the young person does not know, others do not know, how horrible not knowing is and how they are trying to work out who they are but struggling with their developing identity. ‘It is hard having these symptoms’ includes the difficulties with others disbelieving symptoms, disruptions to life, education and

friendships and the struggles of trying to fit within a medical system. 'Trying to get on with my life' captures ways participants are trying to move forward, feeling responsibility for recovery but lacking resources and feeling disempowered, using acceptance or searching for explanations and worrying about the future.

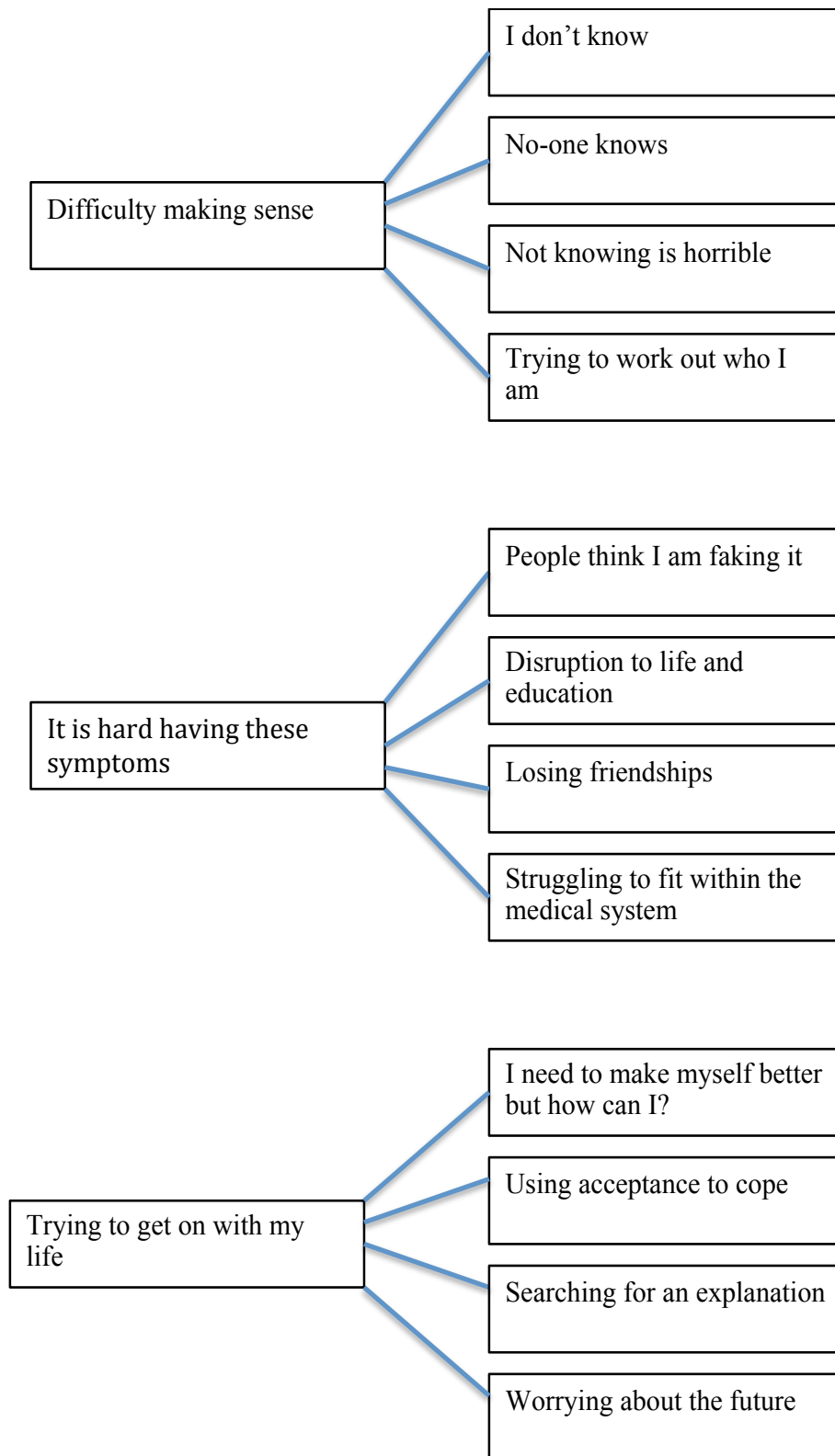


Figure 1. Themes and corresponding sub-themes developed using thematic analysis

3.2.1 Difficulty making sense.

During analysis, it became apparent that all participants had difficulty making sense of their symptoms and their situations. They talked about how they did not have any idea of a cause or explanation for their symptoms, and described the emotional impact of this difficulty making sense. They talked about wanting to have an explanation they could understand, but when doctors and their parents did not know, they could not see how they could know. Making sense also seemed to be important to help incorporate these symptoms into their developing identity, and not knowing contributed to feeling like a “freak”, different to others and not normal. This theme is supported by the sub-themes detailed below.

3.2.1.1 I don’t know.

All participants talked about not knowing the cause of their symptoms, but wanting to know. They did not have a clear understanding about how their symptoms had developed or why they were experiencing these symptoms. As Natalie said: “I just still don’t understand how symptoms are caused, like how the symptom is like there, how does it come” (page 16, lines 373-375).

Participants thought there must be a cause for their symptoms, but did not know what this cause could be. Lucy reported wondering: “where is it, what is it, like does it come from the brain what body part, or if anything, where does it come from?” (page 15, lines 410-411). Some felt that all they really knew was that they were experiencing symptoms or illness. This left them feeling in the dark, confused and without a cause, explanation or understanding of the symptoms they were experiencing. Matthew described the experience as: “just this mystery of what’s what and how it occurs. It’s like playing a game of cluedo really” (page 9, lines 219-220).

Although many participants understood they had been told their symptoms did not have a medical explanation and cause, they found it difficult to think of an alternative explanation and cause, as demonstrated by Natalie:

No I don't think I could, I don't know. I don't think I understood or like how what caused my symptoms. Coz it's, coz he said it's not medical, it kind of made me think oh.. symptoms like, I don't, I don't know what could have caused them. (page 14, lines 343-346).

With a medical explanation excluded, they were left without any idea or explanation for these physical symptoms, and struggled to make sense of this.

Some considered links between the mind and body, and searched for evidence to suggest their symptoms did not have a medical cause. They worked to identify triggers to try and make sense of their symptoms, including keeping symptom diaries, but were not always successful. As Claire reported:

They haven't really found a triggering cause for it and so it's just finding that first link to try and stop it, and there isn't anything to find. We can't find anything there to stop the triggering of problems and everything (page 27, lines 655-657).

In addition, it was difficult to think of these very real, physical symptoms as having no cause within the body, as: "there has to be something going on in the body for it to happen because it's just weird otherwise" (Lucy, page 4, lines 105-106).

Several participants could talk about possible explanations they had been given for their symptoms but then showed difficulty making sense of these and applying the explanations to themselves and their symptoms: "It's like ok that's fine and everything but why. It's like, you understand it and they're telling you it

but it's frustrating because you can't see it in a way." (Claire, page 6, lines 132-133). Claire elaborated on this, accepting that she had been told her symptoms may be caused by stress, and she could understand this in a scientific way but it did not feel like it made sense:

I think it did make sense in a way, like in a like scientific way I can see how stress can lead to this to lead which leads to symptoms but in another way where it's just like yea it, I see that I'm not really in it, if that makes sense. Like I know it's happening and I can see where it happening but I don't really understand the why. I don't know why (pages 5-6 , lines 124-128).

Lucy felt similarly: "I don't see how it can just be emotion coz if it is just emotion then I'm sure like everybody else would have them once in a while as well, not just me and some other people out there" (page 6, lines 176-178).

Participants felt there must be a cause: "I'll sit there at night and I'll just think like there has to be something that causes it and it can't be just happen like that" (Lucy, page 4, lines 103 -104). It did not make sense to the participants that they could be experiencing these physical symptoms without a cause. Overall, it seems without an understanding and explanation for their symptoms, participants struggled to make sense of their experience.

Most participants talked about wanting to know why they had symptoms, and felt it was important for themselves and their families to have an explanation and understanding of their symptoms, because: "I think the more we have guesses of what it is, the more chance we're going to have that I get in defying it" (Matthew, page 18, lines 444-446). There seemed to be an idea that with an understanding or diagnosis, doctors would be able to offer them treatment, as

demonstrated by Kate: “at least you want them to know so they can make you feel better. But they dunno what to do” (page 13, lines 344-355). Therefore it seemed that in addition to helping make sense of symptoms, having a diagnosis, explanation or understanding gave hope for a treatment, a cure and a life without symptoms.

3.2.1.2 No-one knows.

Participants also described how no-one else knows an explanation for their symptoms. They mainly discussed doctors not knowing, and the difficulties this caused.

Participants talked about doctors not knowing the cause of their symptoms, for example Jake said he saw various: “doctors and hospitals and they didn’t know what it was” (page 1, lines 7-8). When doctors did not know, participants found it difficult. Kate described how it was: “hard because if they, they’re obviously trained and they they they’re meant to know like if there’s something wrong and they know how to treat it but if they don’t know then who will know” (page 4, lines 99-100).

Many participants wondered why doctors did not know, or why doctors could not answer their questions. They often assumed that if doctors did not know, there must be something very wrong with them, as illustrated by Kate: “there must be something quite wrong if I’m having to go to all of these like better places if they can’t work out what’s wrong with me” (page 4, lines 88-89). Kate elaborated this, considering no-one knowing to be: “weird because then obviously the first thing that pops into your head is must be bad if no-one knows” (page 14, line 391). This contributed to participants losing hope of being

able to make sense, because: “if they don’t know then who will know” (Kate, page 4, line 100).

Also, doctors not knowing resulted in participants thinking that doctors: “didn’t know what to do” (Lauren, page 1, lines 5-6). When nobody knows: “nobody’s able to answer your questions for you” (Lucy, page 14, line 397) and: “it’s not ok because there’s nothing anyone can do for you” (Beth, page 14, lines 343-344).

Some participants described doctors assigning them a diagnostic label for the sake of having a label, rather than due to an understanding of their symptoms, as highlighted by Claire: “they labelled my symptoms as being down to IBS but that was only because they couldn’t actually find anything else and they kind of just went yea it’s this because there is nothing else we can describe it as” (page 13, lines 304-306). This resulted in confusion rather than being helpful.

3.2.1.3 Not knowing is horrible.

All participants contributed to the sub-theme of ‘not knowing is horrible’, considering what it is like to have symptoms and not have an explanation they can make sense of. As Lucy highlighted: “Like it’s not nice not having an answer to something that you really need to know” (page 14, line 387). Many experienced not knowing as: “rather weird coz we don’t know anything about it” (Matthew, page 5, lines 124), and: “it’s weird not knowing what could cause them” (Natalie, page 15, lines 355-356).

Participants described experiencing a range of emotions in response to not knowing. Several experienced not knowing as worrying as: “you don’t know what’s going on inside you” (Kate, page 1, line 14). Matthew described how:

the last thing I want is to not to not know what it was in the first place, have no idea and not be able to tackle it at all coz that would quite worry quite worry me quite a lot (page 7, lines 171-173).

Others described not knowing as hard, annoying and:

frustrating though coz you're just like, you're sitting there and you've got all these symptoms and you just wanna know what's wrong with you and you wanna know something that will make you feel better and they're just not finding anything (Claire, page 25, lines 610-613).

Some participants described the not knowing as upsetting, for example: "leaving me out in the blank. It's quite upsetting" (Jake, page 38, line 938).

3.2.1.4 Trying to work out who I am.

All participants contributed to the sub-theme of 'trying to work out who I am'.

Young people are developing their identity, and exploring who they are.

Participants struggled to make sense of their symptoms in context of their identity, both individually and as a young person.

Most participants discussed ideas of normality, and seemed to see having symptoms nobody could make sense of as a challenge to normality. As Beth highlighted, many felt: "like you don't belong anywhere" (page 37, lines 406-407). Most saw themselves as: "feeling odd and different from everyone else, like people all over there and then there's just me right over there. It's like everybody's wearing the same coloured clothing and then I'm in a different one" (Lucy, page 16, lines 435-437). In addition Matthew suggested having these symptoms you cannot make sense of: "makes you feel kind of well different, unique from everybody else" (page 5, line 123).

Some participants felt their identity was characterised by their symptoms. For example Beth described: “I was known as the girl who has the seizures and that’s all I was known as” (page 39, line 367-368). Claire had seemed to incorporate the symptoms into her identity, as she reported: “I don’t think of them as symptoms, I think of them as just, they’re there, it’s not a symptom it’s just part of, it’s going to sound really cheesy but part of me” (page 21, lines 517-519). However this seemed to be an attempt to manage incorporating symptoms into her identity knowing she was unable to make sense of them, rather than incorporating symptoms she could make sense of in a meaningful way.

Many participants talked about feeling like a different person to before experiencing symptoms, for example Matthew described: “I guess you feel like a whole different person” (page 10, line 236). Kate reported that: “I can’t even remember what it was like before it so I don’t actually remember what it’s like to not have a tummy ache it’s been so long” (page 7, lines 179-180). Several participants discussed the importance of: “getting back to who I was before” (Natalie, page 9, line 223). Matthew highlighted this: “You feel like your body’s been taken over by something else, possessed almost because it’s just something.. well.. the idea of your body acting in unusual ways and then returning to a prior state is just rather weird” (page 10, lines 236-239).

In addition, Beth described how she had chosen a different name to develop an identity separate from the person she was with the symptoms:

I didn’t mind people calling me Elizabeth but obviously I’m called Beth because I feel like I’ve changed. I’ve got a different name because if people call me Elizabeth, I’m like, I’m not Elizabeth, I’m Beth, it’s not Elizabeth anymore even though it is. Still my mum calls me Elizabeth

because you know but I feel like if I, if they call me Beth they respect me and they know me and who I actually am, not just this girl who has the seizures that everybody feels sorry for (page 40, lines 969-975).

This suggests that for many participants, experiencing these symptoms, and living with difficulty making sense of them has resulted in difficulty developing their identity.

Many participants were struggling to make sense of why were they experiencing these symptoms as opposed to anyone else. For example Leanne reported:

I don't know. That's what I like think all the time, like when I, when I'm ill with it. It's like why does it have to be me? Why isn't it like my sister or my brother or my friends or my family or someone else around the world. Why does it, why's it me? (page 21, lines 503-506).

Many participants felt alone with their symptoms and difficulty making sense of these, for example Natalie described how this: "kind of makes me feel like I'm by myself in a way" (page 4, line 76). However wondering about others with similar symptoms was common across participants, particularly wondering if they were facing similar experiences and if they were able to make sense of their symptoms. Lucy talked about this being important to her and wondered if the researcher would be able to help her with this:

could you ask them like how they feel like about having it and how they feel around other people coz if they have the same affect around me then that would be nice but then if they don't, then it looks like I'm just the only one (page 19, lines 538-540).

Needing to have a sense of shared identity and experience seemed important to enable the development of an identity as a young person incorporating these symptoms. However, the majority of participants had not met another young person with symptoms they were experiencing difficulty making sense of.

3.2.2 It is hard having these symptoms.

Throughout participants' accounts they described how difficult it is having symptoms they struggled to make sense of. Many experienced others as thinking they were faking symptoms and struggled with this. All participants experienced disruption to life and school, losing friendships and difficulty struggling to fit into a medical system.

3.2.2.1 People think I am faking it

Many participants described others not believing them, Jake reported that: "mum didn't believe me" (page 15, line 367). Many focussed on professionals not believing the reality of their symptoms, as Beth explained: "I'm not, not faking it. I want them, what I seriously wanted them to tell me was that they believed me. That they have trust in me" (page 23, lines 564-565). She later elaborated this, remembering: "and then someone tells you you're faking it" (Beth, page 23, lines 556-557). Lucy also highlighted:

I think it's just because it's been said that oh they're not real so many times it's got into my head that they're just going to use that excuse every time it's kind of made me feel that way and think about it (page 2, lines 55-57).

This suggests participants felt they had to justify the reality of their symptoms, and somehow prove they were not faking symptoms. Not being believed also contributed to participants feeling uncared for, as Lauren suggests:

“just a bit, like they didn’t care really. Even though you, I was like, I was definitely in pain and I wasn’t putting it on it’s kind of like they just didn’t care” (page 35, lines 839-840).

Feeling they were not being believed or listened to about the reality of their symptoms led to some participants questioning themselves and querying the validity of their symptoms, wondering: “is there nothing actually wrong with me?” (Claire, page 25, lines 614-615). Also, Claire wondered “am I just overthinking? You start questioning yourself like are over, am I overthinking it” (page 25, lines 613-614). Lucy explained that doctors communicating no medical explanation, and not knowing the cause led to a view of herself as crazy: “I was like have I actually gone crazy, are they saying that? The non-epileptic ones are in my head and I’m starting to go mad” (pages 11-12, lines 317-318). Beth also felt similarly, assuming that not knowing implied: “so I’m mental aren’t I, that’s the, that’s the word you use and they used to call me not normal, and you just think call me mental then” (page 36, lines 886-888).

3.2.2.2 Disruptions to life and education.

This sub-theme was developed to capture the disruption of having symptoms that are difficult to make sense of. Data from all participants were included in this sub-theme. Disruption included to experiences of education and school, life and family life. All participants had missed school due to the symptoms they were experiencing. This ranged from missing a few days for appointments and due to symptoms to Jake, who said he:

missed the whole of year 7 and I was in and out of year 9 and year 8. I was off for 2 weeks in year 9 and it just stopped and off for about a month during year 8 (page 10, lines 235-236).

At the time of the interview, Jake was attending a special school for young people with medical needs. In addition to missing school, many spent time at school but outside the classroom due to their symptoms. For example, Lauren described:

And then when I did go into school, I coz sometimes during school I wasn't able to go into my lesson, I was going into this other room in the school, which was in a room with people I didn't know (page 7, lines 168-171).

Alternatively they may sit within the classroom, but: "just like sit through lessons like just bent over on the table coz it really hurts" (Leanne, page 4, lines 79-80).

All participants discussed worries about their symptoms having an impact upon their school performance. Kate described her symptoms affecting her ability to participate at school: "you can't concentrate obviously you learn a few things but you when you can't concentrate you can't get the most you can actually do" (page 2, lines 54-55). This was highlighted by Lucy worrying:

coz I'm like losing my grades because of being off school I feel like when it comes to May time (*exams*) I'm gonna be sitting in the hall and I feel like when I open that envelope I'm going to have FF or UU's coz I've missed out on so much of the school work and it's kind of like hard to catch up (page 15, lines 420-423).

All participants described not being able to do what they wanted. They had to give up activities or hobbies they enjoyed, and stayed at home more often. For example, Lauren said she:

wasn't able to do a lot. We kind of just, most of the time, just sat and did nothing. Coz I couldn't do anything because I couldn't walk or go out in a car coz of like the bumps and the car and things. So, yea, I just wasn't able to do a lot really (page 2, lines 39-42).

Many participants avoided going out due to worries about their symptoms, for example Claire discussed:

I'd worry about doing things or going out to places like going out with my friends or weekends away because I worried what happened if I felt ill, and I started, my stomach started playing up and things like that (page 2, lines 47-50).

They talked about not being able to manage if they did go out, for example Jake said: "if I do go out, I can't do much coz it hurts too much to do anything and it flares up if I try and move or anything" (page 11, lines 266-267). Some participants felt it was particularly difficult at their age, as Claire described: "especially in your teen years where you get bullied and you get all these teasing remarks" (page 26, lines 642-643). Indeed, several participants reported being bullied at school, usually experiencing verbal comments from peers, although some also reported physical bullying. Lucy described difficulty with bullying when peers knew about epilepsy:

they'll say that I because I had it so many times at school they'll be going along and saying oh well no that's not true, she can't have it and then they'll say sometimes that oh epileptic, she's like that and she's an epileptic, she shouldn't be at this school, she should be at a special school (page 2, lines 34-37).

However, Lucy worried this would be worse if peers knew about her non-epileptic seizures:

I think if they find out about the non-epileptic ones then if they're already telling me that I don't belong at this school, I belong in special school or hospital or I should roll down and kill myself because we don't deserve to be on this planet (page 13, lines 357-360).

Other participants described feeling like they had to be mature, for example Beth described that: "I felt like I had to step up, like I said be all mature, talk more maturely" (page 34, lines 832-833). This resulted in losing childhood: "especially as a child you lose a lot of your childhood" (Beth, page 39, line 964).

Many struggled with missing activities, for example:

when I wasn't able to go, I just kind of, I'd just kind of like, I don't know. Was kind of like a bit upset kind of coz I wanted to do it, I just can't, I couldn't. Like most things, I just wanted to do really badly and I just couldn't do it at all (Lauren, page 21, lines 508-510).

All participants considered the impact of the situation on their family within their accounts, with families experiencing a range of consequences. Many participants shared that their symptoms had caused worry for family members, with for example, Beth: "scared my mum couldn't cope with it" (page 6, line 140). They felt a need to protect their parents from worry, for example Matthew reported: "I don't tend to talk to my mum about it, she's got enough on her plate really. She's got me and Jay and then she's got the worry of obviously me having the fits" (page 16, lines 387-390). Most participants talked about their parents having to miss work or adapt their working hours or location to care for them,

grandparents and other relatives helping to care, and the whole family having to miss out on activities due to their symptoms.

3.2.2.3 Losing friendships.

All participants contributed to this sub-theme encompassing the loss of friendships. They considered how not being able to explain their experiences and difficulties and the related loss of confidence has affected their relationships. Difficulty talking about symptoms featured across all accounts, with many isolating themselves so they would not have to explain.

Several participants reported experiencing a school transition while experiencing symptoms and difficulty developing new friendships as demonstrated by Natalie: “it was hard for me to make friends” (page 2, line 44). Reduced contact with friends due to symptoms or worry about symptoms also caused upset, as described by Claire:

it was, upsetting in a way because in the end people just stopped inviting me to places and I knew they were my friends and everything but they’d always say like oh we went here and we went there and I’d be like yea, I didn’t. So it was upsetting knowing that I could be going to all these places but I’d somehow just not went to them. (page 3, lines 70-74).

Some participants also described a loss of confidence, which resulted in them isolating themselves. Natalie described how:

it started in year 6 it was still going on and coz I was starting like a new school it was hard for me to make friends coz I was so shy about it and really conscious like if I’m friends with them they’ll find out and then like won’t be friends with me in a way. So I was kind of like, it stopped me from going out. I just kept saying I’m ill all the time, which I didn’t

want to do. My confidence just disappeared, I don't know where it went.

Just like, everything just kind of like closed in a bit (page 2, lines 43-49).

Trying to explain symptoms and causes was very difficult for all participants. They talked about having: "no, no ideas at all" (Lucy, page 6, line 166). It was particularly difficult having no language to use to explain, as Natalie reported: "I'll just be like oh my, I can't say what it is" (page 3, line 68). Claire highlighted:

If someone asked me why, I would, I usually just went, because I'm ill, it was just like you would. Like when someone asks you why you've got a cold you just kind of go just because I have and that's what I kind of had to do. Coz there weren't really any other thing I could say, it was just as if it were some other illness I just have to go because of, that's because I do. There weren't anything I could say (page 13, lines 313-318).

Many participants talked about not wanting others to know they had symptoms, and particularly not symptoms they could not make sense of. Many identified they did not like talking about their symptoms to friends or family so avoided talking about them. There was also a sense of being unsure of others' understandings and not wanting to disrupt an understanding they hold. For example, Beth described how:

It's hard when you go round for sleepovers because they're asking you have you took your tablet. And I don't really respond because I don't really have any tablets or I don't, I don't well obviously I don't have anything but I don't want to explain it to them (page 27, lines 653-656).

3.2.2.4 Struggling to fit within the medical system.

Data from all participants contributed to this sub-theme, as they described struggling with the medical system, particularly when their symptoms did not fit within a medical diagnosis or explanation. Many experienced painful and invasive investigations, which often showed negative results. Their accounts included negative experiences with the medical system and professionals.

Expectations of the medical system seemed important, for doctors to: “make it better” (Jake, page 24, line 595). Claire described how:

I came to the doctors because I didn’t want this anymore and I didn’t want to deal with it anymore but I hear I’m being told that I’m just going to have to deal with it for the rest of my life and it was annoying (pages 20-21, lines 494-497).

They also expected explanations from doctors but were not given these, as demonstrated by Lucy:

I go and ask the hospital and they like, they kind of find it hard to explain as well which is quite difficult coz they’re like one of the people I could go to if I wanted to know what something means (page 6, lines 167-169).

Therefore it seems the experience of the medical system when suffering with symptoms without a clear medical explanation conflicted with participants’ expectations and hopes for understanding and treatment.

There was a sense of doctors being powerful, experts and affecting peoples’ experience of the medical system. Beth particularly talked about negative experiences with doctors and the medical system, for example: “they don’t have any respect for me” (page 28, line 677). She experienced doctors as: “arrogant” (page 4, line 80); and: “quite selfish really” (page 4, line 80). Kate

suggested different doctors were better or worse: “doctors are different they weren’t as nice” (page 13, line 358). Others felt dismissed by doctors, and described: “that he was just telling us to go and get a McDonalds and eat it” (Lauren, page 33, lines 803-804), or were told to: “take paracetamol” (Jake, page 4, line 77).

There was some discussion of doctors as respected experts in medical knowledge, as highlighted by Kate: “they’re obviously trained and they they they’re meant to know like if there’s something wrong and they know how to treat it” (page 4, lines 99-100). Participants assumed doctors have a certain knowledge: “well you are professional people like I’m sure you must know like not even like a full story but just like a little” (Lucy, page 7, lines 200-201).

However, there was also a negative side to doctors being experts and making assumptions: “They’re like I said assuming coz they’re literally like I’m a professional” (Beth, page 42, line 1029). Alternatively, as experts there was a sense they may not be sharing their knowledge, as highlighted by Lucy: “Coz you’re never ever going to know, only like professionals like you are training to be will know but people like me will never know” (page 6, lines 152-154).

Participants also talked about doctors not understanding them and their perspectives. Many described doctors talking to their parents but not to them, as highlighted by Claire: “mostly their conversations stayed between my mum or my dad, it was usually my mum, whoever was there and the actual doctor. It was usually just them having a conversation” (page 11, lines 253-255), leaving her without a voice: “and then I’d be sitting here like yep, twiddling my thumbs” (page 11, line 255). Often this, in addition to a lack of confidence or language to

describe their symptoms led to parents talking for the young people when with doctors, and young people feeling excluded.

Claire described the experience of feeling excluded in appointments: it was quite frustrating because it was just, they were talking about me and I weren't like annoyed with it, it was like ok they're talking about me, obviously they need to talk about me. It was just so frustrating because I didn't know what they were talking about and it was like yea this is all great and everything, but what has this got to do with me (page 11, lines 261-265).

However, sometimes doctors were interested in their perspective, and participants found this positive. For example, Claire described:

as much as they couldn't explain it they was always trying to help, talk to you a bit more and try and get, try and get your point of view. Like, I'd always be asked what my symptoms were and how I felt about my symptoms and I got asked that by a lot of doctors (page 14, lines 328-331).

There was also a sense of doctors focussing on the medical side, as Lucy said: "whereas the doctors and nurses they're obviously I'm not in their place and I don't know what their proper job is but like I kind of feel like they're just there for medical reasons" (page 11, lines 296-297). However some young people suggested that doctors should consider broader factors, for example: "I think I would like doctors to ask about your past experiences" (Beth, page 41, line 1013).

Some participants also described doctors telling them they were wrong, as demonstrated by Beth: "there's no feeling that can describe how you feel

when they tell you, no, that's that's not right" (page 4, lines 78-79). Some participants talked about trying to see the situation from a doctor's perspective to have empathy with doctors in this situation. Furthermore, many participants talked about adapting their communication and language to enable doctors to understand them. Beth explained "You have to have that language in the, the room where all the doctors are. You have to speak I call it adult language" (page 14, lines 328-329). Claire demonstrated this:

they always reworded it anyway, so there was, there was no point using these words which I knew if I, if I knew a different word for it which they use, I might as well just use the word they use, that way everyone's on the same wavelength. So there's no point using little words (page 14, lines 345-348).

In contrast to this, all participants described difficulties in understanding doctors and their experiences within the medical system. Most were unable to provide a clear explanation of investigations, results and treatments they had experienced or the reasons for these. In contrast, there seemed to be a pattern of investigations being done to them, and decisions being made without their involvement rather than them understanding and consenting to investigations or referrals to services.

The majority of participants described some difficulty understanding doctors: "coz it was doctor terms and I was only 11" (Jake, page 5, line 118), instead relying on their parents to translate these explanations for them: "but a lot of them were just like, told everything to my mum and my mum was left to try and explain it to me" (Claire, page 11, lines 272-273). As Natalie said: "But I

think, if I didn't ask my mum, I'd still be confused now" (page 13, lines 310-311).

Those with a medical diagnosis but experiencing symptoms beyond those explained by their diagnosis struggled to understand their diagnosis, for example, Leanne reported: "well I went to the, they, the hospital diagnosed me with, I can't I don't know how to say it but it's like eosinophilic enterocolitis or something" (page 4, lines 92-93). When asked, Leanne was unable to elaborate further or describe what this diagnosis means.

Regarding treatment, the majority of participants talked about the negatives of medication they had been prescribed. They discussed a range of side effects, some long-lasting, as experienced by Jake: "they caused heart palpitations which were a lasting effect after I came off them. I'm still getting them occasionally now" (page 6, lines 132-133). Medication was also a burden, as supported by Beth: "They were making me even more stressed. Like I'd walk out the door, oh my god have I took my tablets. You know oh my goodness" (page 42, lines 1022-1023). Also, for many medication did not seem to help: "I was on morphine as well actually and it that wasn't, that wasn't helping that much" (Lauren, page 15, lines 352-353). However, they struggled mostly to make sense of how: "the past god knows how many years, they've been giving me the wrong medication, or at least medication that's not necessary" (Matthew, page 11, lines 272-273).

In contrast, all participants viewed psychology as helpful, particularly in showing understanding and trying to help participants make sense of their symptoms and experiences. For example, Kate described: "yea it sounded spot on what she was saying. Everything she was saying" (page 8, line 209). Many

also referred to coping strategies they had been taught as valuable and helpful in beginning to manage their symptoms, such as: “she was basically just going to teach me some self-help techniques to deal with pains and she did. She helped a lot” (Claire, page 28, lines 693-694).

3.2.3 Trying to get on with my life.

All participants talked about their ideas of both learning to live with the symptoms, however difficult this may be, and worrying about the future. Their ideas of beginning to move forward are discussed within the four sub-themes that were developed, presented below.

3.2.3.1 I need to make myself better but how can I?

Through participants’ accounts a sense of responsibility for recovery was identified, but conflicted with feeling disempowered, confused and excluded. Several participants seemed to adopt responsibility for making sense of their symptoms, talking about trying as hard as they could to find an explanation. For example, Beth reported: “And I try I remember every night I used to try and figure out what was wrong with me” (page 9, lines 217-218). Claire described using her knowledge of science to try and find an explanation: “we’re doing the immunity and little sicknesses anyway and so I tried thinking of it in a scientific way as in that way” (page 27, lines 652-654) whereas others tried to research their symptoms, including looking on the internet.

Research also seemed to be helpful and through participating in interviews for this research and sharing accounts, participants were contributing to the understanding. This was highlighted by Matthew: “I think the more research we put into it and the more chance of finding out what it’s going to be”

(page 20, lines 475-476). It also seemed important to find a cause themselves to prove the reality of their symptoms, as demonstrated by Lucy:

It's horrible like you just wanna say to them I'm not faking it at all. It's like if there's a way I could prove to them that I'm not faking it then I would use it but there's no way I can prove it to them (page 13, lines 367-369).

All participants' accounts contributed to an understanding that it was their responsibility to cure themselves of their symptoms or learn to manage their symptoms. Many saw symptoms as: "just something I have to deal with" (Leanne, page 21, line 499) and "something I have to kind of get through" (Lucy, page 17, line 465). Participants talked about trying things to improve, ranging from medication to coping strategies such as distraction:

not ignore it as in ignore its entire existence but just kind of ignore it as in like getting on with it and pushing it to the back of my mind and just kind of moving forwards without making a big, huge fuss and kerdaddle (Claire, pages 27-28 lines 668-671).

They described following the advice of doctors and being determined to try their best, as demonstrated by Beth: "Like it is now, I'm it might be hard but I'm committed to make it better, not forget but to put it behind me and move forward" (page 35, lines 854-855).

This sense of responsibility was especially pertinent when symptoms were understood as not having a medical cause, as explained by Natalie:

the medicine helped to clear it but then because they've said it's not medical, I should be able to do that myself. Without the medicine, so it's kind of like reflecting back, thinking like I can do that, I need to do that

coz I know it's not medical. So it kind of like makes me understand like I could try this. I know that I can do it, it's not medical like is one thing that's out of the list that it's not (pages 20-21, lines 491-496).

However this sense of responsibility to treat their symptoms contrasted with not knowing how to do this. Despite trying, participants expressed: "there's nothing really you could ever do about it" (Lucy, page 3, line 65). Leanne talked about needing to manage the symptoms, but when asked how, she could only say: "I don't know don't know" (page 23, line 545). Although feeling a responsibility, participants often felt powerless against the symptoms, as highlighted by Lauren: "there wasn't a lot really. Just had to get on with it really. I suppose and just when the pain went, it went really" (page 27, lines 647-648). They felt unable to cope and needed help to manage the symptoms, as shown by Claire: "I couldn't deal with the pain, it would be helpful to have something to help deal with it" (page 29, lines 700-701).

3.2.3.2 Using acceptance to cope.

All participants' accounts suggested trying to find a way they could cope and manage the symptoms they were experiencing and the difficulty making sense of these symptoms and situations. Most participants seemed to use acceptance as a way of trying to cope. There was a sense that this was the only option for them, as highlighted by Beth:

because to cope with it, I just have to get on with it. I couldn't, I can't just sit about thinking poor me because you have to get on with it, for your friends, for your family and for yourself really (page 12, lines 289-291).

Most participants described trying to continue with their lives, such as Kate: "just get on with what I usually done before that" (page 1, line 26).

Some participants seemed to accept explanations given to them as a way of trying to make sense, such as Matthew: “I’ve just gone along with what people have said” (page 18, line 443). Ideas of accepting that there may not be an explanation or meaningful way of making sense of the symptoms were identified, for example seeing symptoms as “A bug that can’t be fixed at the moment” (Claire, page 26, line 632). Also, accepting that making sense would be good, but difficulty making sense can be accepted: “and if it does then that will be really good but if it doesn’t then life goes on” (Lucy, page 6, lines 157-158).

3.2.3.3 Searching for an explanation

Some participants thought having an explanation would help them get on with their lives. This seemed to be very much a way to cope rather than their symptoms having a meaning they can make sense of and so has been differentiated from the theme of ‘difficulty making sense’. Kate and Claire discussed ideas that there was an undiscovered medical explanation. Kate tried to make sense of her symptoms by assuming that doctors not knowing meant “there must be something quite wrong” (page 4, line 88). Claire made sense of her symptoms medically, saying: “I know it’s because I’ve got an illness” (page 22, line 523). This was reinforced by her experiences with professionals, and the understanding “but then obviously if there wasn’t they wouldn’t continue and say keep on taking, there’s obviously something there” (pages 25-26 , lines 619-621).

Others tried searching for triggers or incorporating ideas from others, resulting in participants forming a range of tentative understandings, from viral triggers and a weakened immune system to anxiety and stress as a cause. For

example, Kate attempted to make sense of her symptoms using ideas from professionals:

they said that I got a tummy I got a bad like period where I was ill and then straight after I got another period where I was ill and then that it couldn't my immune system couldn't cope with it so it's just like it made it like this for like two years (page 3, lines 80-82).

In contrast, Matthew described working collaboratively with a psychologist to attempt to make sense:

we've come to the decision that it's actually been based upon stress and it seems coz obviously at the time when I was when it all started occurring obviously my mum and dad, they were going through a tough time and there was arguments almost every day every other day and so basically they think that the stressful environment I was in has started to cause obviously all this (page 1, lines 7-12).

Indeed, any explanation participants could use for communication was seen as helpful, even if participants did not believe the explanation themselves. Many participants had developed explanations they could use to communicate with others and provide a language for this to help them move forward. Several used explanations of food as a cause, citing common allergies that are likely to be understood by others, for example Leanne explained: "yea it's all because of like my allergies" (page 5, line 102). Others described the symptoms they were experiencing, in a similar way to explaining it to doctors, such as Claire:

mostly what I would say to the doctor like oh I get stomach cramps and I bloat up and I feel sick and I get diarrhoea and things like that. I mostly

just say what I, what I say to the doctor to them. Maybe not as in-depth but overall the same thing (page 16, lines 394-397).

Many gave explanations given to them by doctors, often using medical explanations, as these seemed easier to communicate and for others to understand. Beth demonstrates this, explaining: “I’d say I have epilepsy because that’s the only thing I knew because if I didn’t say that then there’d be more questions and all of that so yea” (page 20, lines 480-481).

3.2.3.4 Worrying about the future.

All participants contributed to the sub-theme worrying about the future. All wondered about the length of time symptoms would continue for, and worried about the effects of their symptoms on their future lives.

Most participants expressed concern that their symptoms would continue, or would improve and then return, especially participants whose symptoms had begun to reduce, or were feeling more able to manage symptoms. Lucy highlighted a shared fear of not being able to cope with symptoms increasing: “I’m just gonna fall back down again like a broken jigsaw puzzle” (page 16, lines 454-455). Some participants perceived their symptoms to be a long-term condition that they were powerless against. For example, Matthew described how he expected his symptoms to feature in his future: “probably the rest of my life or until this clears up which is probably going to be .. quite late into my life if it does” (page 8, lines 193-194).

In contrast, many participants held hope for the future, for example that an explanation would be found, they would be able to make sense of their symptoms and a treatment would cure their symptoms, as demonstrated by Lucy: “I just hope one day that there would be like like you will know and then able to

tell us” (page 6, line 156). Others also discussed their hopes for the future, such as: “obviously I want to go off to university or I want to get a job, I want to move out of my parents house” (Claire, page 21, lines 507-508).

However the accounts suggesting hope for the future and ideas of life as an independent adult did not incorporate experiencing symptoms into this future. Many participants worried their symptoms would cause difficulty in their future, both in the next few years and over a longer period. For example, Natalie worried: “is this going to stop me from doing things in the future or is it going to be an on-going thing where you can’t stop it” (page 9, lines 201-203). Leanne also worried about the impact of her symptoms on her future exam performance, and achieving qualifications she would rely on later in life: “I’m worried like what’s going to happen next. Like if this still carries on when I’m like in year 11, what will it do? Will I like fail all my GCSEs and just really worrying” (page 26, lines 619-621).

Discussion

4.1 Overview

This section provides interpretation of the results to answer the research questions, with each research question considered in turn. The findings from the current study are discussed in the context of previous literature. A critical appraisal of the current study is offered, and implications for clinical practice and future research considered. Excerpts from the researcher’s reflective log are presented in separate text boxes throughout the chapter.

4.2 Summary of Study Results

4.2.1 How do young people experience medically unexplained symptoms?

This broad research question aimed to capture the whole experience and so the majority of the themes and sub-themes developed from the data provide information to answer this research question. Overall, the results suggest young people experience MUS as incredibly difficult and affecting their life across all areas. The results provide insight into the daily struggles of living with MUS, for example in missing school and activities and being bullied by peers. Participants experienced difficulty managing their symptoms, and found they did not have a language to share their experiences. This led to many participants isolating themselves and losing friendships. In the context of school transitions and increasing independence, the experience of MUS was particularly difficult.

An important part of the experience of MUS was anxiety around others not believing the reality of their symptoms, or thinking they were ‘faking’ symptoms. For some participants, these anxieties extended to worrying they were inadvertently exacerbating or causing their symptoms. Many described difficulties in communication resulting in them battling to be understood, but struggling with the resources available to them as a young person.

Experiences were also characterised by struggling to fit into the medical system. Participants had difficulty understanding the medical system, doctors and the justification for the invasive investigations and treatments they received. Many spoke about the language doctors used and relying on their parents to translate this so they could understand, or adapting their own language in an attempt to develop a shared language so doctors could understand them.

Within the experience of MUS was participants' need to find a way of managing and living with their symptoms. This included using acceptance to cope or searching for explanations. They worried about their future, with hope for a symptom-free future.

4.2.2 How do young people make sense of their symptoms?

The results of this research suggest young people experience difficulty making sense of their symptoms, which has a negative impact on other areas of their life. Participants struggled to make sense of their symptoms, finding not having a comprehensive explanation that is meaningful for them very difficult. Other people not knowing contributed to confusion. Not knowing is difficult and the emotional impact of uncertainty is considered.

All participants tried to make sense of their symptoms, identifying a personal responsibility for recovery but struggling with this in the context of feeling excluded and disempowered. Young people may expect to share possible explanations with others to build a shared understanding of difficulties and to help them make sense of their symptoms and experience. However, having no language to talk about symptoms creates barriers to these conversations. To try to manage this, some used language and explanations others might understand, such as food allergies or stress.

Although some participants were able to give a limited explanation of their symptoms in the interview, it became apparent they did not understand this explanation. They had adopted it as the only way they could talk about their symptoms and experiences. Often this explanation was given to them by a professional and interpreted by their parents. This became apparent when they were unable to expand on or clarify the explanation they provided.

4.3 Discussion of Study Findings in Relation to Literature

A review of the literature highlighted a lack of published studies regarding the experiences of young people and how they may make sense MUS. Therefore, although the findings of the current research are discussed in relation to published literature and theories, this is generally as a comparison to the published literature relating to adults with MUS. However, findings are also considered alongside research conducted with parents of children with MUS and children with other illnesses and medical conditions.

4.3.1 Difficulty making sense.

The difficulty making sense identified for young people in the current research is largely consistent with published literature related to adults' ability to make sense of MUS. In line with research by Carton et al. (2003), young people had a poor understanding of their symptoms, any diagnosis and were unable to develop a coherent and meaningful explanation for their symptoms from medical consultations. In addition, they also experienced uncertainty related to the lack of a coherent explanation which was meaningful to them, as reported in adults with MUS (Nettleton, 2006; Nettleton et al., 2006). This suggests the difficulty making sense is not specific to young peoples' cognitive ability or stage of development, but a shared experience for people with MUS.

Records in the reflective log following each interview suggest accounts given in interviews in the present research often seemed to lack clarity, an idea of a timeline or order of events and suggested general confusion. This is demonstrated by the following excerpt from the researcher's reflective log:

I have noticed across most interviews, participants' stories often seem confused, and it is difficult to establish any sort of timeline of events, with many participants unclear on even how long they have experienced symptoms for. However, it's not just the timeline, the accounts often seem to jump around with some gaps and inconsistencies. This seems to be something reflected in the reflective log for each interview so far, and I wonder if this confusion in the account reflects any confusion in experience or the confusion that comes from accessing multiple services, and experiencing symptoms that are difficult to make sense of.

This is consistent with qualitative research exploring adults' experiences of MUS, which suggested accounts developed through interviews were complex and often showed signs of confusion, a lack of clarity and difficulty constructing a coherent timeline, difficulty defining the beginning, progress and any sense of an end (Green et al., 2004; Nettleton et al., 2004; Nettleton et al., 2005). These findings are also consistent with Green et al. (2004) that adults had confusion about cause, illness identity and experience. They assumed this resulted in difficulty expressing ideas about the timeline of their symptoms and their management. These findings are consistent with the current research, but no causation is inferred. This difficulty constructing a coherent narrative of symptoms and experiences may be particularly difficult for young people, with more limited language and resources to have their account heard. This may represent the confusion experienced by participants, suggesting interviews may be valuable, with the interview process providing additional insight into the experience.

Participants found it difficult that others did not know the cause of their symptoms, particularly when this was doctors or their parents. With young

people, adults usually provide support and resources to help them make sense of perplexing situations and experiences. However, this is not possible with MUS as parents and professionals are also unable to make sense of their symptoms. This is supported by Stone (2013b), who reported doctors also experience difficulty making sense of MUS, resulting in difficulty providing explanations, predictions of prognosis and providing effective intervention. This may be due to not having access to a holistic explanation that incorporates a whole mind-body perspective. Doctors also found it difficult having no name or label to talk about the symptoms and acknowledged a label could help validate symptoms and experiences.

Therefore doctors and patients may share a similar experience in difficulty making sense of symptoms and recognition of the advantages of a label and language. However, there does not seem to be a communication of the shared experience in the difficulty making sense. Instead this difficulty is experienced individually without recognition of the similar difficulty experienced by the other. This difficulty may however have a different meaning for each party involved.

Stone (2013a) suggested that without a meaningful narrative for their illness or symptoms, it is difficult for adult individuals to incorporate their symptoms into their identity and view of themselves. In the current research, participants struggled with their developing identity and trying to work out who they are. In a similar way to Stone (2013a), the current research suggests young people also struggle to incorporate their symptoms into their identity due to their difficulty making sense of symptoms and being unable to access a meaningful narrative for them.

In the current research, this also led to participants questioning whether they were normal, and struggling to develop a view of themselves that made sense, at a critical time when their identity may be developing (Meeus, 2011). This could contribute to on-going social isolation due to feeling different from peers and not normal, anxiety regarding the way others view them, or difficulty establishing a coherent self-identity, resulting in long-term difficulties.

Therefore, in a similar way to previous research, the current research identified difficulties in making sense of MUS. This resulted in lacking a language to communicate effectively, difficulty incorporating symptoms into identity, and presentation of difficult to follow accounts. In addition, this difficulty making sense may be shared by all parties involved but not communicated.

These findings can be considered within the context of the Uncertainty in Illness model (Mishel, 1981, 1988). Although not intended to be an explanatory model for causation of illness, the model provides insight into factors contributing to difficulty making sense of and adjusting to illness. The findings of the current research support this model in that ambiguity concerning the condition, lack of information about the diagnosis, unpredictability of prognosis and complexity regarding treatment and the healthcare system were all relevant to participants and identified as important in their accounts. Although participant experiences can be understood in-depth, a causal relationship cannot be established within the current study, and so the relationship between these factors and difficulties cannot be examined. However, all the factors listed were identified alongside difficulty making sense of symptoms.

In addition, although attempts to adjust to symptoms were identified through the ‘trying to get on with my life’ theme, this theme also included participants’ reports that despite trying their hardest to alleviate or learn to live with their symptoms, they found this incredibly difficult and had varying levels of success. Therefore, this suggests the Uncertainty in Illness model can be helpful in understanding the experience of MUS and the difficulty making sense of symptoms. In addition, this suggests that reducing uncertainty, or interventions to help manage uncertainty may provide improvements for young people with MUS.

4.3.2 It is hard having these symptoms.

Young people found it very hard living with MUS. This theme captures the experience of daily life with MUS, and can be considered alongside research exploring adult experiences of MUS. In a similar way to reported in adult literature, young people discussed difficulties with social relationships. However, there were some differences in the focus of discussion. For example, accounts of young people focused on maintaining friendships when limited activity and missing school resulted in less contact with friends, whereas literature for adults focuses on roles in relationships, fear of burdening others and social isolation (Green et al., 2004; Lempp et al., 2009; Nettleton et al., 2005; Toye & Barker, 2010).

In addition, Green et al. (2004) reported adults with MUS were withdrawing themselves from social contact, but only one participant reported being rejected by friends, and no participants discussed stigma. However, stigma was relevant for young people participating in the current study, with many reporting bullying, receiving nasty comments from peers and believing others

would not understand, resulting in social isolation. This difference may reflect the life stage of young people; developing understandings of relationships, roles within relationships and social experiences.

Indeed, Jelbert et al. (2010) reported that young people with CFS described a sense of social loss, with losing relationships, interpretations of social judgement by others and a perception of being alone; similar experiences to participants in the current research. They also identified academic losses, recognising the negative impact of symptoms on education, again an experience shared with participants. Therefore, young people with MUS may experience similar disruptions to daily functioning to children with other illnesses and symptoms.

Participants also questioned the legitimacy of their symptoms, and wondered if their symptoms were real, consistent with that described by adults (Toye & Barker, 2010). This may lead to further isolation for a young person, including within their family system. The implications of this may include defensiveness, holding rigidly onto a medical explanation, disengaging from services and symptoms escalating or becoming more debilitating, and further affecting functioning.

In a similar way to research exploring mothers' perspectives, participants described disruptions to family life and their parents' working lives, particularly when extra care was needed, they were unable to attend school, or siblings' activities were disrupted (Morris & Ogden, 2012). This suggests research exploring parents' experiences and perspectives may provide some insight into perspectives of young people. This is perhaps unsurprising as both parents and young people live within the family context, and share the same medical

encounters. Within the parent accounts, a need to protect their child against threat was suggested, particularly any suggestion symptoms were not real, or caused within the family context (Morris & Ogden, 2012). This may align to young people in the current study feeling disbelieved.

Therefore, in line with previous research, participants experienced many difficulties as a result of their MUS, including disruptions to life and relationships. Due to their age and different context to adults, they also struggled with losing friendships and disruptions to education.

4.3.3 Struggling to fit within the medical system.

All participants identified struggles with the medical system. The identified sub-theme of ‘struggling to fit within the medical system’ can be related to published literature. Within the western medical system, people expect to attend a doctor to seek help, be given a diagnosis they can understand and related treatment (Stone, 2013a), an expectation supported by participants in the current research.

However, with MUS these expectations are not met, with patients instead struggling with symptoms which do not allow this journey, resulting in them experiencing a system unable to provide a diagnosis and often effective treatment. MUS also pose significant challenges for medical professionals, not following the predictable pattern of investigation, results, diagnosis and treatment that doctors are trained to provide. Making a decision to cease investigations following negative results and remaining uncertainty causes significant anxiety for doctors (Stone, 2013a).

Related to this, Salmon et al. (2005) reported finding that although patients often sought explanation and emotional support, they were instead given physical interventions, including medications. Although the current research

does not allow a clear understanding of young peoples' expectations for the intervention offered, a difficulty with medication as intervention was identified. Many participants discussed experiences of unnecessary medication, suggesting they may have preferred no medication. In addition, the provision of a medically based treatment resulted in confusion if they understood their symptoms did not have a full medical explanation, contributing to difficulty making sense of their symptoms.

This struggle to fit within the medical system is also consistent with a qualitative exploration by Nettleton et al. (2004), suggesting many felt frustration living with symptoms which could not be understood or treated and despite experiencing physical symptoms, not feeling accepted by the medical system.

Participants described difficulty when doctors were unable to provide answers, experienced medical encounters as questioning the reality of symptoms and desired a diagnosis to enable access to treatment. These are similar to families' difficulties identified by Carter (2002). Carter (2002) also reported that young people felt ignored, with their accounts reinterpreted by professionals through their own understanding. This was also identified in the current research. This suggests professionals should reflect on their own assumptions regarding MUS, and the impact of this on their understandings of the experience of MUS.

In response to their stories being reinterpreted, many participants in the current research described using doctors' language to enable a shared understanding, although it is unclear if this communicated their full perspective. This also creates barriers to professionals understanding their experiences and their difficulty making sense of their symptoms.

Therefore the current research supports previous research that the medical system causes difficulties for those with MUS. These are related to expectations of the medical system, difficulties with communication and not feeling understood.

Findings from the current research support those of the Plymouth project (2009), that the current system for people with MUS is inefficient, struggling to fit within the medical paradigm and results in unnecessary referrals, investigations, stress and dissatisfaction for the client. This results in a dilemma of wanting and needing a system which is unable to provide answers. Also Hinton and Kirk (2015), identified communication between families and professionals was problematic. This led to misunderstandings and dissatisfaction shared by all parties, with families reporting receiving inadequate information and professionals reporting a lack of knowledge and expertise. The families' experience was supported by this research. It is acknowledged the shared difficulty making sense results in a lack of adequate information to be given to families.

As suggested by Furness et al. (2009), paediatric staff acknowledge the complexities of working with young people with MUS and perceive these as resulting in extra demands and anxieties for professionals. They reported lacking the appropriate skills, expertise and knowledge to work with children with MUS. Therefore, although one suggestion is the current medical system proves disappointing for families, perhaps more important to consider is enabling the system to manage professionals and families being unable to make sense of symptoms and struggling to identify effective intervention.

4.3.4 Trying to get on with my life.

Young people with MUS were trying to move forward with their lives but facing challenges. Of the literature reviewed, there seemed to be very little exploring the way people with MUS were able to move forward with their lives, either with or without on-going symptoms.

Adults reported experiences of relatives or friends becoming involved in trying to help them move forward, by seeking diagnoses, noticing symptoms or pursuing new treatments (Nettleton, 2006). Due to the nature of healthcare services for young people, and the reliance on parents as gatekeepers and providers of support, it would be expected that this would feature heavily in accounts. In contrast, a responsibility for personal recovery was identified in the current research. However, there was also a discussion of reliance on parents to provide explanations for symptoms to others and lead appointments with professionals. This suggests perhaps parents were involved in help-seeking but as this would be expected within the family roles, it did not feel different or interesting to emphasise in their accounts. Yet, the feeling of responsibility may have developed in response to others being unable to help, and others may have been more involved earlier.

4.3.5 Explaining disparity with the literature

Despite many similarities with previous research, there are also some differences. The current research focuses on young people, who are likely to have very different experiences to adults due to the context they are living in, the role of families and family contexts and stages of development (Eminson, 2007). In addition, young people have limited control and power over their lives and activities such as medical encounters. They are often dependent on others,

particularly their parents, for information, aiding decision-making and enabling access to activities and medical encounters. They are limited in the choices available to them across life, but also specifically with consenting to medical procedures, treatments and referrals to other services (Edwards & Titman, 2010; Eminson, 2007; Weisblatt et al., 2011).

Therefore, it would be reasonable to expect differences between adults and young people in their experiences and the way they make sense of symptoms. The young person's stage of development and cognitive ability may affect their ability to make sense of their symptoms and experience and the language and resources available to support them with this. In addition, at a time when identity is developing, young people are separating and becoming more independent from their carers and beginning to broaden life experiences. Therefore it may be expected that young people have more difficulty making sense of their symptoms and experiences than adults.

Carter (2002) explored three families' experiences of having a young person with chronic pain. They identified a family focus on difficulty with professionals, and language describes more of a battle, with a "quest for diagnosis" (p. 28) and referrals building hope, later dashed. Participants in the current research described difficulties with the medical system, but less of a battle, and this was only part of their accounts. Participants desired an explanation and language they could use, rather than describing a pursuit of a diagnosis per se. Referrals were also assumed to result in more difficult encounters rather than hope. In addition, Carter (2002) reported that parents felt their own explanatory frameworks were dismissed.

However, the report lacks transparency, and it is unclear if the experiences and perspectives differed between family members. The power of family members and the effect of their voices may have differed, and these differences may be explained by a focus on parental perspective in contrast to the young person. The medical trajectory and professional knowledge and training may have improved since the research was conducted, resulting in continuing difficulties but improvements.

4.3.6 Learning from broader literature.

Due to the limited research regarding young people with MUS, findings from the current research are considered alongside research exploring experiences and perceptions of children with different diagnoses. Periods prior to diagnosis, or confusing diagnoses with uncertain prognosis may contribute to similar experiences of difficulty making sense and uncertainty.

Despite being a recognised diagnosis, controversy and a lack of clarity, including around aetiology surrounds CFS (Jelbert et al., 2010). Many experience a period of diagnostic uncertainty and barriers to accessing effective treatment (Webb et al., 2011). There were some shared experiences with young people with MUS, particularly with medical services, including feeling dismissed, not listened to, and feeling the reality of their symptoms was questioned. Similarly they also experienced diagnostic uncertainty, although this resolved when a diagnosis of CFS was given (Hareide et al., 2011; Jelbert et al., 2010; Richards et al.; Webb et al., 2011). This suggests difficulty negotiating medical services and feeling dismissed whilst without a diagnosis is common across conditions, but this improves upon receipt of a diagnosis. This suggests on-going difficulty for young people with MUS.

In contrast, young people with CFS were more able to make sense of their symptoms, usually providing an explanation of an organic aetiology with an illness trigger and activity as a maintenance factor (Hareide et al., 2011; Jelbert et al., 2010; Richards et al., 2006; Webb et al., 2011). However, it is unclear how they have reached a position where they are able to make sense of their symptoms, or if this explanation is meaningful for them. This may be an explanation provided by professionals that they are able to understand and apply to their own experiences. Whilst experiencing diagnostic uncertainty, they also experienced personal and academic loss and social isolation although this improved with receipt of a diagnosis and effective intervention (Jelbert et al., 2010).

Receiving a diagnostic label is also likely to contribute to sense-making and enables young people to have a language to talk about their symptoms, share their experiences, and incorporate their symptoms into their developing identity. The diagnosis also allows access to specialist services and evidence-based intervention. However, despite shared experiences of uncertainty, young people with MUS are unlikely to receive a diagnostic label and the benefits this brings.

Research exploring parent perspectives may also provide helpful insight into the perspectives and experiences of family systems. Madeo, O’Brine, Bernhardt and Biesecker (2012) investigated factors contributing to perceived uncertainty in parents of children with a condition undiagnosed at the time. They found that as uncertainty reduced, control and optimism increased, and subjective disease severity was positively associated with perceived uncertainty. They suggest that as parents experience greater uncertainty, they feel less control over their child’s condition, which may lead to poorer adaptation to illness.

Kerr and Haas (2014) explored uncertainty in parents of children with birthmarks, a condition they argue results in increased risk of misdiagnosis, inconsistent information being provided, and requires the care of different specialist services. They reported parents described a range of uncertainties, including concern about their child's future and the impact of their condition on their life. They also suggested the combination of inadequate information and conflicting perspectives and advice elicited more uncertainty. The current research findings can be interpreted alongside these findings, with similar uncertainties and concerns reported by participants in addition to difficulty in response to inadequate or conflicting information. This suggests young people and families experience increased uncertainty as a result of inadequate information, which causes them concern regarding their future.

The current study findings are consistent with a synthesis review of patients' experiences of uncertainty in illness by Hansen et al. (2012). In a similar way to the current study, the review found uncertainty was explained by a number of factors including awaiting results and diagnosis. They also identified emotional consequences of uncertainty, including worry and loneliness, emotions also experienced by participants in the current research. Responses to uncertainty included trying to re-establish normality and learning effective coping strategies, also similar to participants in the current study. This suggests uncertainty causes significant difficulties. However, this review included participants with medical diagnoses, and found learning about and adjusting to a diagnosis to be important in responding to uncertainty, a barrier for people with MUS.

Overall, this suggests that others with diagnostic uncertainty share similar challenges and experiences, with difficulties resolving following diagnosis.

However, by definition, MUS are unlikely to result in a diagnosis or understanding, suggesting on-going difficulties.

4.3.7 Mason's concept of safe uncertainty.

Due to the shared difficulty making sense of MUS, and the uncertainty this promotes, consideration of uncertainty, and managing uncertainty may be helpful. Mason (1993) considers uncertainty, our drive towards certainty and solutions, and the different possibilities of uncertainty, as being paralysing or enabling creativity, although he acknowledges the need for some perceived certainty. This research in addition to previous research suggests there is uncertainty with MUS, and this is unlikely to change. In the current research it seems participants experience this uncertainty as unsafe, with insecurity in relationships, the present and future, and this is causing additional difficulties and preventing the development of ways of managing and moving forwards with MUS.

Uncertainty is a concept used in family therapy, with therapists adopting a position of uncertainty in order to collaboratively explore the meanings and ideas a family bring. Mason (1993) suggests professionals are able to guide families towards a shared position of safe uncertainty; flexible with evolving collaborative narratives, new explanations alongside current, curiosity and moving away from the need for a fixed solution that fits everyone. This stance may be helpful for professionals working with families with MUS, allowing them to access and gain insight to families' experiences and perspectives. This concept may also be relevant for individuals and families and professionals experiencing MUS, and may provide a way for people within the system to work

with MUS. Working towards a position of safe uncertainty rather than searching for an elusive diagnosis or solution may enable moving forward.

4.4 Critical Appraisal of the Current Study

A critical appraisal of the strengths and limitations of the current research is offered below.

4.4.1 Qualitative framework.

The current study utilised a small-scale qualitative design to explore how young people experience and make sense of MUS. Therefore results are not intended to provide claims of the relationship of the sample to the general population, or the significance of the results to the general population (Willig, 2013). This is a limitation of the study, alongside other qualitative studies. However the results provide an in-depth insight into the accounts and experiences of the participants, and may also be relevant to others of a similar age experiencing MUS.

4.4.2 Sampling.

One limitation of the current research is the sampling. Due to ethical regulations, clinical psychologists based at each site identified potential participants and made the initial contact. The researcher was only able to contact potential participants if they provided consent to be contacted. Although necessary to protect client information, and psychologists were asked to approach anybody meeting the research inclusion criteria, this may have resulted in some selection bias. However the impact of this is limited as the qualitative approach from a critical realist perspective does not intend to generalise results to all people with MUS and data are intended to represent the experiences of the sample.

Participants were at various stages of the journey through services, although all had completed medical investigations and had been told doctors

could not find a full medical explanation for their symptoms. Some participants were currently receiving psychological sessions, whereas others had received brief psychological intervention, and others were waiting for sessions with a psychologist. This may have impacted on how they made sense of their symptoms and the explanations they could use, particularly as intervention may have involved constructing a shared formulation of their difficulties. Due to the research being small-scale it was not appropriate to compare participants' accounts based upon their time with psychologists. This would also have been difficult, due to the involvement of a number of psychologists across the services, and the possibility of differences between psychologists and their ways of working.

In addition, participants were recruited from two sites and were scattered over a large geographical area. This meant participants had very different experiences of services and different journeys of assessment, referral, investigation and feedback. However, all participants talked about their experiences of the medical system within the interviews, and analysis suggested that despite different experiences and journeys, there were also commonalities in participants' experience and the way they made sense of this.

There were no restrictions on the type of MUS experienced by participants, and this resulted in a sample of participants experiencing a range of symptoms. However, it was assumed all would be sharing the experience of having symptoms they were told doctors could not find a full medical cause for. This was supported by data analysis that suggests that although symptoms differ, all participants contributed to themes regarding a shared experience of these symptoms, and the difficulty making sense of these. In addition, Aamland,

Malterud and Werner (2014) suggest considering different types of MUS as one condition, due to large similarities across MUS, co-morbidity with other MUS and the possibility of shared underlying mechanisms.

4.4.3 Interviews.

Although all participants were offered a choice of location for the interview, eight chose to have the interview at home, and one at the clinic they usually attend. This difference in location may have changed the conversations and may have impacted on anxiety and engagement levels. The participant who chose the clinic was one of the earlier participants, and it was not known that all others would choose their home. However, care was taken to ensure the interview at the clinic was conducted in a separate room to the room they usually attended.

Interviews conducted at home were in a room where doors could be closed to ensure privacy for the interview and all parents were encouraged to leave the room after completion of forms, with the permission of their child. However, Jake chose to have his mother stay for the interview to help him manage his anxiety. We agreed this was his decision, but asked his mother to sit quietly to allow a focus on Jake's perspective and account. However, concern about the impact of having his mother present is highlighted in the following excerpt from the researcher's reflective log:

Regarding Interview 9: I found it difficult that Jake wanted his mum to stay for the interview, and his mum seemed to want to stay too. I am concerned it may affect the interview, or that it's building the interview up as something to be worried about. But I am keen to listen to Jake as I don't want him to feel dismissed and not listened to. In other interviews, all participants and parents have been happy for the parent to leave the room when requested. I hope that our agreeing his mother would stay silent will minimise any effect on the research process, as I need to be careful to ensure I stay attuned to Jake's account rather than his mum's. I was aware of actively ignoring mum and not looking at her while really focussing on Jake. I hope it has not changed the conversations we have too much.

All interviews were conducted by the same trainee clinical psychologist and reflections and assumptions recorded before and after each interview. However a pattern in the reflections was a concern about upsetting participants, and a desire to allow participants to tell their stories without pushing them for more information they seemed reluctant to give, as highlighted by the below excerpt from the researcher's reflective log:

Generally I've been noticing in interviews I'm curious and want to find out more, but I am worried about upsetting the participants. Nearly all have talked to me about finding it hard talking to strangers, or adults or even people they know, particularly people they don't know about their symptoms and I fit with nearly all of them! I'm not sure if maybe I could push them to find out more, but I'm really grateful they are taking part in my research and I feel like I need to make this as pleasant for them as I can. I wonder if hearing their stories of being ignored, not listened to and dismissed is making me want to protect them from me and not add to their list of bad experiences with professionals. I'm aware of trying to use my clinical skills in being curious and following their lead without pushing them towards an explanation and hoping this is enough. At times, I worry this makes it seem more like a psychology session than a research interview though. Although it seems to be working, and I have a lot more data than I expected and I hope all participants have found the interviews ok. Some are even giving me feedback that they have enjoyed the interviews and have found them really helpful so maybe I'm being overly critical.

In addition, it was explained to all participants and described in the research information sheets that the interviewer was a trainee clinical psychologist. However it is possible not all participants understood services and professional roles and so were unlikely to fully understand the role of a trainee clinical psychologist and where they may fit within the complex medical system. This may have shaped some of their accounts, including language used, expectations of the interview and the way they talked about their experiences with services and professionals.

4.4.4 Focus on the individual.

The current research focussed on listening to the story of the individual and exploring their experiences and how they make sense of their symptoms. This

allowed in-depth exploration of individual accounts and experiences and in an area lacking research into this, provides valuable insight into the experience. As part of their accounts, all participants also included some consideration of systemic and family factors, including impact on their family, school and negotiating through a complex medical system. However, as an inductive approach to analysis was adopted there was not a particular aim to explore issues related to the wider family experience and systemic factors. This leaves a focus on the individual perspective, which is a limitation of the current study.

Young people live within their family context, and with parents often acting as gatekeepers to healthcare services. Indeed, many parents also provide support within contact with services, often providing descriptions of symptoms, and translating the doctors' language to their child. Therefore family is likely to be an important part of the experience. Exploration of the family perspective and experiences for the whole family could be an interesting extension of the research.

4.4.5 Data analysis.

Evidence of analysis at all stages is available if requested to increase transparency. An extract of a transcript with codes assigned is provided as an example in Appendix C. However, in line with a critical realist perspective, it is accepted that the researcher's perspectives will have influenced data collection and analysis (Braun & Clarke, 2013). Reflective memos were created throughout the process of data analysis, and as evidenced by the amount of codes generated from the data, analysis was thorough. However, the reflective log suggests motivation to ensure data are coded and analysed thoroughly to allow the participants' voices and accounts to be listened to. Discussions in research

supervision highlighted difficulty making decisions in analysis, particularly when discarding smaller groups of codes, or codes only endorsed by one participant, due to a fear of not representing a story fully. This contributed to analysis possibly to the extent of the researcher trying to diminish their own assumptions and perspectives as demonstrated by the following excerpt:

After discussions in research supervision today, I've realised I may be working too hard to analyse the data really thoroughly and not miss anything. I think after feeling I have been fighting to get this research through and peoples' voices heard and hearing in the interviews, that this is really important to my participants, I want to make sure I am doing their accounts justice and telling the stories they want to be told. This is probably why I have coded each transcript so thoroughly and have ended up with so many codes generated. At times it feels overwhelming with the amount there are. It means I still have to make judgements though about what stories are going to be told, and what data and codes will be brought together to create groups of codes and eventually themes and what will be discarded. Its hard realising that I can't possibly include it all, and I want to do the best I can to represent their voices, but I know my perspectives and assumptions will also influence this.

However, the use of the reflective log and discussions in research supervision highlighted this as a limitation of analysis, and an area to be overcome during the later stages of analysis. Comparisons across the different sites or types of symptoms may have been interesting but was beyond the scope of this research, and would have been limited by the small number of participants.

4.4.6 Credibility checks.

Considerations of methodological rigour are discussed in detail within the method chapter. The research was conducted consistently with these plans for

ensuring the trustworthiness of the research. Transparency in the presentation of the research and analysis has helped to achieve coherence. All themes and sub-themes presented are grounded in data examples, with extracts from transcripts presented throughout the results chapter. Recordings were reviewed alongside transcripts to ensure consistency and to provide context. Interview transcripts were returned to throughout all stages of analysis to ensure the themes and sub-themes identified were held within the data and told the stories of participants. Research supervision was used throughout. As planned, participant verification was not used due to concerns around threats to confidentiality and the assumption participants may feel pressured to share this with others, including parents.

4.4.7 Reflexivity.

The use of reflexivity is a strength of the current research. A reflective log was kept throughout the research process. Research supervision enabled reflection of the researcher's position and effects of their perspectives and assumptions throughout the research, with a particular emphasis on this during data analysis. This use of reflexivity is consistent with the critical realist perspective, and excerpts of the reflective log have been presented within this chapter to enable transparency and allow readers to consider the data within the context of the researcher's perspectives.

4.4.8 Dissemination.

A strength of the study is the planned dissemination of the research. All participants were offered and accepted general feedback from the research. This summarised the key findings across the group of participants and was presented in a format they could understand. The summary of findings for participants is

provided in Appendix O. There are also plans to disseminate the findings through presentations to multidisciplinary teams within services supporting the research, and to publish the research in a peer-reviewed journal.

4.5 Implications for Clinical Practice

The results from the present research suggest a number of important implications for clinical practice, including for intervention and improving experiences within the medical system.

4.5.1 Implications for the medical system.

The current research suggests young people with MUS experience difficulty negotiating their way through the medical system. This is perhaps unsurprising considering their symptoms do not fit within the medical paradigm, or the expected course of seeking consultation, diagnosis, treatment and recovery. All attended appointments at a number of services and met a range of doctors across specialities.

4.5.1.1 Improving communication with young people.

Communication difficulties featured heavily in accounts, with young people feeling confused and excluded in consultations. For some, this resulted in them developing a medicalised language professionals could understand. Sifneos (1973) suggested MUS may be a physical presentation of difficulties with identifying and expressing emotions. Gilleland et al. (2009) highlighted children with MUS have poor awareness of emotional experience and difficulties with emotion regulation. Both suggest MUS are a communication of this difficulty and distress. If MUS are conceptualised, at least in part, as a form of communication of emotional or psychological distress, this difficulty in communication may increase distress and so exacerbate or maintain symptoms.

Therefore improving communication, and enhancing emotional understanding may alleviate distress and possibly some symptoms. It would also be helpful for medical professionals to have an understanding that symptoms may be a physical manifestation of distress.

All participants relied on their parents for support negotiating this complex system, to translate the words doctors used, and provide care and explanations. However, even with parental support, their journey through the medical system was confusing. The current research is unable to answer whether parents were successful in developing their own understandings of the process, the systems and making sense of doctors' explanations to then translate these for their children.

This suggests it would be important for doctors to provide explanations of the process, their understandings and to explain any referrals, investigations or interventions in a way that makes sense for the whole family. This implication is consistent with that derived from a synthesis of research exploring patients' experiences of uncertainty. This highlights the importance of an organised and supported trajectory through healthcare systems (Hansen et al., 2012).

Language used in consultations was often a source of difficulty for participants. However, a few participants discussed doctors using language they could understand, and invariably found it helpful. Others discussed pretending to understand, suggesting doctors may need to check young people have understood their explanations. Many participants adapted their language to ensure doctors' understood them, and although they were sometimes unsure of meanings of the words, they knew they made sense to doctors. This suggests a shared

communication problem, and professionals may improve this by adapting their language.

4.5.1.2 Communication of a belief in the reality of symptoms.

Another difficulty identified in the current research was that young people often felt others believed they were faking their symptoms, including medical professionals. A contributing factor was the difference in language used between young people and doctors to describe similar symptoms. Participants also made assumptions when they were told there was not a medical explanation for their symptoms. The current research is unable to provide any insight into the perspectives of the doctors involved, including their belief about the reality of the symptoms. Therefore participants' beliefs may reflect doctors' beliefs or they may be a result of the interactions. This suggests doctors may need to convey explicitly their belief in the reality of symptoms despite being unable to identify a medical cause. Further research exploring doctors' experiences and perspectives of consultations with young people with MUS could focus on doctors' beliefs around reality of symptoms and inform consultations.

4.5.1.3 Training for medical professionals.

This research suggests a role for specialist training for medical professionals. Training could involve acknowledging the challenges of working with patients with MUS and supporting medical professionals in developing specialist skills to enhance their skills and confidence. The relationship of doctors working with young people with MUS and their families is important to maintain engagement and prevent unnecessary investigations, referrals and physical interventions. Engagement at this point is essential for engagement in further interventions or

services which could offer support and development of resources for managing symptoms.

4.5.2 Intervention.

The current research has a number of implications that are relevant for interventions for young people with MUS.

4.5.2.1 Making sense of symptoms.

The current research suggests young people experience difficulty making sense of MUS, and this causes them considerable difficulty across their lives.

Throughout interviews, no participant was able to make sense of their symptoms. However, it seemed through sharing their experiences and telling their accounts in interviews, participants were working to try to make sense of their symptoms, with many participants suggesting the process was helpful for them. This may have allowed them to explore the experience of having symptoms they could not make sense of, and allow them to begin to accept this uncertainty.

The ability to build a shared collaborative understanding of symptoms which takes account of parent and young person beliefs about the symptoms is argued to be essential for engagement in any intervention (Garraida, 2010; Hardwick, 2005). Explanation of symptoms and constructing a shared understanding was identified as the most important factor in building engagement (Chew-Graham et al., 2011). Indeed, no intervention would be successful without engaging the young person and their family. In addition, NHG guidelines recommend physicians need to work with patients to co-create an understanding of symptoms in a way that makes sense to the patient (Olde-Hartman, Blankenstein et al., 2010). This would need to accept symptoms in the absence of medical pathology as legitimate and incorporate holistic approaches.

However, this assumes there is a sense to be made of these symptoms, which can be constructed between a patient and professional. The current research suggests young people are unable to make sense of their MUS. Although some have constructed an explanation with professionals as recommended, they had difficulty applying this to themselves and their own symptoms. This research suggests participants often feel alone with their symptoms and difficulty making sense, and feel responsibility for managing this uncertainty independently.

Although research suggests the young person, family and professionals share this difficulty making sense of symptoms, the shared nature of this difficulty is not discussed. Professionals, families and patients are striving to make sense of symptoms. An improvement would be an acknowledgement of these processes, the shared difficulty, the striving to make sense of symptoms and the impact of this on all within the system. Recognition of this could lead to more helpful discussions around the difficulties of living with symptoms which do not make sense. The focus could shift to living with and learning to manage this uncertainty, empowering young people to move forward with their lives.

4.5.2.2 Use of medication.

The majority of participants described negative experiences with medication, including side effects that usually outweighed the benefits, and medication feeling like a burden. Participants also found it difficult to make sense of being prescribed medication for symptoms that they have been told there was not a full medical explanation for.

Research within the adult literature suggests doctors often prescribe medication as they assume that medication is expected by the patient, and so by

prescribing medication they are meeting the patients' needs and expectations (Ring et al., 2005). Doctors may also feel they are helping. However, in line with adult literature it seems that young people do not necessarily expect medication, but prefer intervention that allows them to manage their symptoms, such as psychological intervention. Therefore, this suggests the use of medication, and explanations of any medication prescribed and reasoning behind this should be carefully considered, and the costs and benefits for prescribing medication considered for each individual. However, the current research literature does not provide information around parents' expectations and views around medication being prescribed for young people with MUS.

4.5.2.3 Holistic approaches to patient care.

This research also has implications for moving towards a system incorporating holistic approaches to patient care. MUS provide challenges for the traditional medical system and suggest a more holistic approach to patient care, including consideration of the family, social and environmental context the young person is living within would be beneficial. This would be aligned with more biopsychosocial understandings of health and illness, and could benefit from a multidisciplinary care approach. It is likely this would result in a formulation of difficulties specific to the individual and family and a tailored intervention plan.

The current research demonstrates working with a clinical psychologist in the context of developing skills to manage symptoms was perceived as helpful by these young people and families. Indeed, some participants identified a willingness to discuss non-medical aspects which may be contributing to their symptoms with their regular doctor. This suggests families may value a more holistic approach. Adopting a holistic approach would also be important with

young people from a safeguarding perspective, with a view to ensuring safe and consistent care.

Some professionals hold assumptions that referrals to psychology may imply to families they are questioning the validity of their symptoms (Furness et al., 2009). However, hospital-based psychology services seemed acceptable, particularly when participants understood the referral as to help them find out more about their symptoms and ways for them to manage them. This is consistent with findings reported by Griffin and Christie (2008) of the difficulty engaging families referred to psychiatric services who report feeling blamed for causing symptoms and are likely to become defensive and less open to working collaboratively.

This suggests that for young people with MUS, referrals to psychology would be more acceptable if the psychology service is hospital-based and integrated into the medical team, supporting guidelines from IAPT (2008). Referrals should be explained in a way that validates the reality of symptoms, and psychological intervention should be explained as to help make sense of and manage symptoms experienced. However, it is acknowledged this implication is based on the data collected from participants who were willing to access hospital-based psychology services and this may not represent all young people with MUS and their families.

Psychological intervention would be an important component of the holistic approach. The current research suggests when working with young people with MUS, an important component is listening to them, their accounts, experiences and hypotheses regarding their symptoms. Importantly, they must feel believed and the reality of their symptoms validated, in line with

recommendations from Chitnis et al. (2014). An individual formulation of difficulties is helpful, incorporating wider systemic considerations, including education, social isolation, bullying and living within the family context.

Although holistic multidisciplinary programmes have been found to be beneficial for young people with MUS, these often incorporate an inpatient admission (Griffin & Christie, 2008; Koslowska, English, Savage & Chudleigh, 2012). Aspects of these approaches applied within outpatient and community settings may be more realistic and cost-effective. This may include family-based work, such as psycho-education, individual and family therapy, and working with schools to support young people with MUS and reduce social isolation.

4.5.2.4 Opportunities for group interventions.

The majority of participants talked of wanting to meet others experiencing MUS, to share experiences, advice and discuss how they were feeling. Many felt alone with their symptoms. Within clinical practice, groups are becoming more common. Group interventions provide a platform for discussion, sharing experiences and the formation of support networks. The development of groups for delivering evidence-based intervention, or building shared understanding of difficulties is possible. Groups may enable sharing and developing resources for coping with and managing symptoms. In addition, the group setting is time and cost-effective, with the potential to reduce waiting times to access psychological intervention. Evaluations of these groups and the possible development of a manualised group intervention programme for young people with MUS could also be an area for future research.

4.6 Suggestions for Future Research

The current research could be extended in a variety of ways. Using a larger sample size to allow exploration of more experiences and accounts, tightening or extending the age range for participants, or interviewing patients before a referral to psychology could extend the research. In addition, exploration of experiences and sense-making within one symptom cluster or comparison of different types of symptom could be another avenue for future research.

In addition, experiences of others within the system could be explored. Many parents wished to share their experiences. They suggested their accounts might enhance those of their children, provide more context and another perspective of the experience. This would be an interesting avenue for future research, and would allow the perspectives of parents to be considered, and their stories to be told.

Specifically, future research could explore the experiences, or how, and if parents are able to make sense of their child's symptoms. Within the current research, all young people talked about the impact of their symptoms on their families. It may be interesting to explore how parents manage when they are unable to provide explanations and alleviate the symptoms their child experiences.

In addition, research exploring the process of negotiating services would be helpful and could be explored from individual and family perspectives, leading to understanding of similarities and differences within this process. A possible extension may be focusing on the process of adjusting to receiving a diagnosis of symptoms without a full medical explanation. This could be explored over a period of time to enable understanding of the process of

adjustment for the individual and their family. It may be valuable to conduct this research using a grounded theory approach, enabling the development of understanding of these processes.

In addition to exploring these processes from the individual and family perspective, it would be useful for research to incorporate the perspectives of medical professionals. This could be completed by interviewing different members of the system, including the young person, parents and doctors during their contact with services and following feedback of a diagnosis of MUS.

To address the limitation of this research including young people from different stages of the process through the medical and psychological system, future research could focus specifically on young people at one point of the process. For example, all participants within the current research had accepted a referral to psychology services, and were either receiving some sessions of psychology or awaiting these. Future research could focus on young people who have not accepted a referral to psychology, and who may be pursuing further investigations or medical treatments.

However, this is very difficult, particularly when research is seen to be aligned with psychology. Feedback received from psychologists supporting recruitment for the current research suggested families who were unhappy with referrals to psychology did not wish to participate. In addition, medical consultants were reluctant to approach families who had refused referrals to psychology, due to concerns about the research information highlighting the researcher was a trainee clinical psychologist.

All participants were white British, although there were no inclusion or exclusion criteria around ethnic origin. Therefore it would be interesting for an

extension of this research exploring how young people experience and make sense of MUS across cultures and ethnic origins. This may reveal differences in making sense of symptoms, which could be important to inform clinical practice.

Research exploring longer-term outcomes may be helpful. Difficulty making sense of symptoms may affect longer-term symptom experience. Future research could therefore explore the effects of this difficulty on the wider experience. This could include coping, functioning, symptom intensity and frequency, and view of the self, in addition to recovery from symptoms.

In addition, if research suggested this difficulty making sense caused further difficulties, or affected the longer-term experience, this would suggest interventions focussed on helping young people make sense of their symptoms may be helpful. This may take the form of developing a shared understanding of the difficulties as recommended by NHG guidelines (Olde-Hartman, Blankenstein et al., 2013). However, it is unclear how successful this approach is, or the likely content of any shared understanding. Therefore, future research examining the efficacy of these interventions, and impact on factors including the symptoms, functioning or experience may be helpful.

In summary, there are many suggestions for future research, including involving different members of the system and their experiences, families who did not accept a referral to psychology and longer-term follow-up studies.

4.7 Conclusion

This research has involved a qualitative exploration of how young people experience and make sense of MUS. A review of the published literature regarding MUS highlighted a lack of research representing the perspectives and experiences of young people with MUS. In addition, a range of possible

explanations and interventions for MUS were identified, although the evidence-base is inconsistent. Clinical guidelines and literature recommend professionals should work with people with MUS to jointly construct a shared explanation and narrative for symptoms. However, research suggests patients and doctors are misinterpreting the others' perspectives, resulting in difficulty constructing these explanations. Therefore the present research aimed to explore how young people experience and make sense of MUS.

Themes identified through inductive thematic analysis suggested young people had difficulty making sense of their symptoms and found it hard living their daily lives with these symptoms. Participants made active attempts to move forward with their lives by developing explanations they could use when talking to others. They tried hard to manage and reduce their symptoms, but were struggling to identify how to do this. They also experienced particular difficulty and frustrations negotiating their way through the medical system. Their experiences were characterised by interactions with professionals they were unable to understand, invasive investigations and ineffective medication.

Strikingly, despite recommendations for development of a shared explanation of symptoms, research suggests professionals and families experience difficulty making sense of MUS. The present research suggests young people also struggle to make sense of MUS. With this difficulty, construction of a shared understanding and narrative which is meaningful for all parties is likely to be very difficult.

In addition, discussions of this shared difficulty making sense are avoided, which maintains difficulties in interactions, anxiety and dissatisfaction. Young people and families feel the reality of their symptoms is being questioned,

negatively impacting on engagement and therapeutic relationships. Furthermore, it may result in feelings of isolation and increased uncertainty for all parties. This may lead to families and professionals seeking further investigations for an explanation to decrease this uncertainty.

These difficulties are considered in the context of uncertainty and recommendations are made for professionals to work alongside families in sharing and managing this uncertainty, rather than pursuing an explanation. This shift in emphasis of working towards a position of safe uncertainty could enable young people with MUS to move forward with their lives, in the way they wish to.

Further clinical implications were suggested, including specialist training, a holistic approach to care and improving communication. The research was critically appraised, with suggestions for further research made to address limitations. Additional suggestions are made for future research to further empower young people with MUS. Exploration of the perspectives and experiences of others in their system, including professionals and family members is recommended to work towards providing more effective and satisfying care.

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Appendices

Appendix A: Contextual questionnaire

Appendix B: Interview guide

Appendix C: Extract of Participant's transcript with codes assigned

Appendix D: Researcher reflections on the development of the research

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Appendix F: Proportionate review confirmation

Appendix G: Research and Development approval from Great Ormond Street
Hospital

Appendix H: Research and Development approval from Queen Elizabeth
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Appendix I: Parent/carer research information sheet

Appendix J: 16-17 year old participant research information sheet

Appendix K: 11-15 year old participant research information sheet

Appendix L: Parent/carer research consent form

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Appendix O: Summary of results sent to participants

Appendix A: Contextual Questionnaire

Participant Demographic Information Form

Please complete the following information about your child. Please provide as much information as you are happy to.

1. What is your child's gender?
 - Male
 - Female
2. How old is your child?
3. What ethnicity is your child?
4. What symptoms does your child experience? (List as many as you can think of)
 - a.
 - b.
 - c.
 - d.
 - e.
 - f.
 - g.
5. How long has your child experienced these symptoms for?
6. Please list the different professionals/specialities your child has seen.
 - a.
 - b.
 - c.
 - d.
 - e.
 - f.

9.

7. Please list any investigations they have had.

1.

2.

3.

4.

5.

6.

7.

8. Please list any support or interventions your child has received.

a.

b.

c.

d.

e.

9. How much input from psychology (currently and previously) has your child had?

a. Currently:

b. Previously:

10. Has your child stopped any activities since experiencing these symptoms (e.g. attending school, clubs, sports)? Please list any

Is there anything else important for the researcher to know?

Thank you for completing this form.

Appendix B: Interview guide

Preliminary Interview Schedule

Participants' own language will be used throughout, and the interview schedule and introduction adapted to the individual's level. For example, "symptoms" will be replaced by the symptoms/difficulties they describe using their language.

Language will also be adapted to the individual participant.

Thank you for meeting with me today to talk to me about your symptoms. I want to remind you that what we talk about will stay confidential, which means I won't tell other people. But if anything you say means I am worried about the safety of you or others I have to tell people who need to know, like your parent/carer and clinical team. If this happens, I'll tell you first.

I may use quotes from what we say when I write the results of the research, but any names or places and other information which means someone could tell it was you will be changed.

If you want a break, or want to stop then please tell me. If you don't want to tell me that you want to leave, please just show the card you have been given, or leave it on the chair when you leave. There will be some time at the end to talk about anything that you want to talk more about or just to have a chat. I want to record us talking today but this will be our voices only. Do you have any questions before we start?

Throughout use general prompts as necessary. For example

- Can you tell me more about that?
- What is that like for you?

Q1. SYMPTOMS

- If its ok, can you tell me why you see a doctor here?
- What was happening to you that made your (parent/carer/self) take you to the doctor?
- Apart from these things do you have any other feelings or problems in your body?

Q2. EXPERIENCE

- What's it like to have these symptoms?
- How do these things affect your life?

Prompt for impact on home and family, education, friends, activity.
Think about negative and positive effects.

- How about the different tests or investigations to try and find out what's causing these? What was that like?

Q3. UNDERSTANDING OF SYMPTOMS

- What do you understand about the results of the tests?
- Can you tell me what you think might be happening with your body?

Prompts if necessary: What was it like the first time you experienced the symptoms? Did it change over time? Prompt to find out process. Does this understanding make sense to them? If someone else was here that had the same symptoms, how would you explain to them what is going on?

- Who have you spoken to about your symptoms?
- What is it like talking to others about your symptoms?
- Has anyone or anything else helped you try to work out what might be happening?

Q4. ANYTHING ELSE

- Is there anything else that you think I should understand?
- Do you have any suggestions for me about our interview?
- Is there anything I could ask other young people to help me find out what its like to have these symptoms?
- Or how they understand their symptoms?
- What would you ask others to find out what its like?
- Or to understand their symptoms?

Thank you very much for talking to me about this. Your answers will be written up and then I will look at them with other young people's answers.

Have you got any questions about this? Would you like to think or talk about our chat?

Discuss as appropriate

Appendix C: Extract of Participant's transcript with codes assigned

R: so what's it like to have these seizures?

P: ...well....obviously at the time it's a bit stressful for everybody including me, its obviously it it sets me back coz I have to have recovery time just to get myself straight, sorted out and it has a knock on effect coz obviously work and school and sometimes it can be quite devastating but since about what last year, end of end of yea, end of 2012 it was actually easing and I wasn't having so much time off because obviously the recovery it so I think its eased definitely and its.. I think the only thing about them is they're really stressful that's all I can really say because... again I don't give it too much thought... I've always just tried to ignore the fact that my epilep, well whatever it is, I cant call it that now that I just ignore the fact that I have the fits just because otherwise I'm just gonna be holding myself back ... and its, mums always been worried about me going out places and things like that but obviously now I've just said to myself that I shouldn't be worried too much as long as I've got precautions, and things like that I should be fine, its not going to be the end of the world and I mean it shouldn't be one of that things that should bring me down

R: and you said that you can't call it epilepsy anymore

P: no, coz obviously it's gone from several stages. The epilepsy, the seizure disorder and now.. well I don't know what it is I am just going to call it fits. Stress-related fits coz.. that's all they are really there's no illness or condition about it, its just fits

R: and what's it like, not knowing what it is and what to call it?

P: ... its.... It doesn't bother me too much to be quite honest as long as I know what's going on and what's happening and we got ways to tackle it, that's all

Me 24/8/15 21:43

Comment [1]: seizures stressful for everybody

Me 24/8/15 21:43

Comment [2]: seizures set me back

Me 24/8/15 21:43

Comment [3]: affects school performance

Me 24/8/15 21:43

Comment [4]: devastating

Me 24/8/15 21:43

Comment [5]: less impact as symptoms reduced

Me 24/8/15 21:43

Comment [6]: seizures stressful for everybody

Me 24/8/15 21:43

Comment [7]: can't call it epilepsy now

Me 24/8/15 21:43

Comment [8]: try to ignore have fits

Me 24/8/15 21:43

Comment [9]: holding myself back

Me 24/8/15 21:43

Comment [10]: mum worries when I go out

Me 24/8/15 21:43

Comment [11]: try to carry on

Me 24/8/15 21:43

Comment [12]: change in understanding

Me 24/8/15 21:43

Comment [13]: changed label

Me 24/8/15 21:43

Comment [14]: call it stress-related fits

Me 24/8/15 21:43

Comment [15]: no illness

Me 24/8/15 21:43

Comment [16]: need to know whats going on

that matters to me to be quite honest. The last thing I want is to be... well...

the last thing I want, the last thing I want is to not to not know what it was in

the first place, have no idea and not be able to tackle it at all coz that would

quite worry quite worry me quite a lot so yea. That's all. Its not it's not too

big of a deal really.

R: and has there been any point over the last years where you haven't

known what it is and haven't known how to tackle it?

P: no. obviously at the very start, obviously it had just started out I didn't

know what it was.. but we still knew how to tackle it coz obviously as

medical training goes if you're gonna have a fit they'll give you certain things

for it. But they thought at first it was related to migraines and bits because I

had suffered with them quite a lot obviously my parents arguing quite a bit

so now its evident stress brought those migraines and bits on and we think

that's what's, we've come to the conclusion now conclusion even that's

what's happened. It's the stress and to be quite honest, I'm wondering why

we didn't see it in the first place.

R: why do you think you didn't see it in the first place?

P: well.... I guess we just overcomplicated things coz there was bits we

couldn't explain, we didn't think it was that simple so... I guess if it was,

there's things we can't explain or well we just think its something...

something a bit more complicated and its, I guess its not right in some cases

but we've got to this stage now and I'm happy that we've got there because

otherwise I think I'd have been I'd have been on those I'd have been on that

those tablets for probably the rest of my life or until this clears up which is

probably going to be .. quite late into my life if it does so it'd be quite nice, I

Me 24/8/15 21:43

Comment [17]: need ways to tackle it

Me 24/8/15 21:43

Comment [18]: worry if couldn't tackle it

Me 24/8/15 21:43

Comment [19]: not knowing is worrying

Me 24/8/15 21:43

Comment [20]: didn't know at start

Me 24/8/15 21:43

Comment [21]: medics know how to treat fits

Me 24/8/15 21:43

Comment [22]: thought related to migraines

Me 24/8/15 21:43

Comment [23]: stress is the cause

Me 24/8/15 21:43

Comment [24]: wondering why didn't see before

Me 24/8/15 21:43

Comment [25]: overcomplicated things

Me 24/8/15 21:43

Comment [26]: assume complicated if can't explain

Me 24/8/15 21:43

Comment [27]: happy have understanding

Me 24/8/15 21:43

Comment [28]: will symptoms stop

don't want to be dependent on them because I'm taking about what I think about I was taking about 10 tablets a day and that's ... 2mg I think of prezotrofen and I think about 800mg of sodium valporate and that was morning and night so its quite a lot to be taking and its quite a heavy burden on my shoulders, trying to remember them in the morning and the evening. Yea even now I've got to admit sometimes I'll forget but I'll be reminded obviously to take them But no, its well I guess its just one of those things really and I do actually thank all the staff here for helping out. Dr (name), obviously, oh god Psy2 because obviously they've gone through things with me and they've backed me up when obviously ... things went wrong coz initially I wasn't initially I was going off to ... I think it was H5 and the doctor I was seeing well he wasn't the greatest person in the world and he insisted that I was put on a high dose of a certain type of drug, I can't exactly remember what it was ... but obviously I was instantly on the floor after taking it. We don't know what exactly it was that caused it so obviously we asked for a second opinion we came here and after that they've done quite a bit for me and I'm quite happy, quite happy about that even if I did have to go to the child centre down there

Me 24/8/15 21:43

Comment [29]: don't want to be medication dependent

Me 24/8/15 21:43

Comment [30]: lot of medication

Me 24/8/15 21:43

Comment [31]: burden of medication

Me 24/8/15 21:43

Comment [32]: staff supportive

Me 24/8/15 21:43

Comment [33]: better doctors

Me 24/8/15 21:43

Comment [34]: negative impact of medication

Me 24/8/15 21:43

Comment [35]: requested second opinion

Me 24/8/15 21:43

Comment [36]: staff supportive

Me 24/8/15 21:43

Comment [37]: seen in childrens centre

Appendix D: Researcher reflections on the development of the research

Initially I planned to use a quantitative methodology; exploring emotional regulation abilities in young people with MUS. Possibly a comparison with young people with similar symptoms, impact of symptoms and pain levels but where symptoms had a full medical explanation. Although received positively by the psychologists consulted, it became apparent that this would need a large sample, which would be very difficult to recruit from this population within the time frame. Therefore I returned to the literature and discovered that despite many articles purporting factors contributing to MUS or interventions for MUS, found very little exploring the perspectives and experiences of the people with these symptoms. Instead perspectives and experiences of doctors had been explored. I was surprised their perspectives and experiences were not represented when this felt so important. Therefore a new idea was formed, and clinicians consulted.

One service that had provisionally agreed to support the research did not think this was helpful for their patients and withdrew their support. I thought this highlighted the lack of value placed on young peoples' experiences and stories and increased my motivation to complete this research. Fortunately, the two other clinics valued and continued to support the new project.

There seemed to be many hurdles along the way, and this research often felt like a battle. Interestingly, as there was less certainty about the possibility of the research continuing, I found myself moving between positions of pushing towards certainty to ignoring and avoiding the difficulties. I wondered if this reflected in any way the experience of MUS, if this had similar uncertainty and what the impact of this is for young people. I incorporated some of these ideas

when developing the interview guide, and considered these in reflections before and after interviews.

Appendix E: Researcher reflections on experiences contributing to the research

I am a 27-year old female white British trainee clinical psychologist. I have always lived in England, except for 6 months when I lived in South-east Asia. Until beginning the doctorate in clinical psychology, I worked in London. I particularly enjoyed the fast pace of life and the diversity of culture, people, opportunities and experiences. I moved to Norfolk to begin the doctoral training and adjusted to the slower pace of life but miss the striving and forward-thinking nature of working in London and the diversity. This affected my decision to approach a London service for the research, to meet my desire to go back to a forward-thinking, diverse service.

Towards the beginning of my developing interest in psychology, I travelled to Cambodia and volunteered with a charity ran by Buddhist monks. From this, I learnt the importance of calmness, respect, patience and listening and developed strong values around these. I also discovered a motivation to listen to, understand and try to help others. I enjoyed exploring and learning about a different culture, watching and observing others to learn the unspoken rules. Around this time, I learnt the value of accepting uncertainty and watching and listening carefully. I heard wonderful accounts, stories and experiences that left me fascinated. I believe this interest in listening to the stories and experiences of others impacted on the development of this research and the research design. I am aware the interest in uncertainty and acceptance may impact on my analysis of the interviews, as I assume these may be concepts talked about.

During my undergraduate degree, I completed a placement in London, within a specialist neurodevelopmental service. While there, I began working part-time as a therapeutic care worker on the adolescent inpatient ward. The ward specialised in working with 8-17 year olds with MUS, and was where I first came into contact with young people with MUS. I found the idea of MUS intriguing and was able to attend various specialist training and teaching sessions focussing on MUS; developing my interest further.

Working on this ward also taught me the value of listening to young people and asking what they think. While I was there, the ward was refurbished to a specification designed in conjunction with the young people. I could see the positive impact of their involvement and listening to their perspectives. It gave value to their ideas and empowerment at a time when they had little power or control over other areas of their lives. This experience and reflections on the experience contributed to my value of the importance of listening to young people, their experiences and stories.

However, I noticed in contrast to this, the treatment model adopted meant young people were not asked about their symptoms. Although this may have happened in individual therapy sessions, staff were trained to not acknowledge signs or suggestions there may not be a full medical explanation for peoples' symptoms. Despite the value of honesty and exploring perspectives in other areas, discussion of symptoms and explanations of symptoms seemed to not happen. Even in this environment, designed using a therapeutic milieu model, discussion of experiences and making sense of MUS was not valued.

I noticed improvements, and young people became symptom-free and left the ward. However, one challenge in discharge planning was what to tell people,

friends and school to explain their absence? I'm not sure we found the correct answer for this, but the explanation agreed was often a medical narrative of illness and a hospital stay. I wonder about the impact of this on the way people make sense of their symptoms. This was a real challenge and resulted in my having questions regarding how young people can talk about and make sense of their symptoms.

These experiences and reflections have informed the ideas behind the research, the design, research questions and method of data collection. I am now in a position where I hope to be able to explore these. I have also developed assumptions about ideas or topics that may be important and am aware these may impact on data analysis. I assume that there must be uncertainty that is difficult to manage. I assume that young people will have difficulty making sense of their symptoms, and I am curious about how they have managed to do this, and to what extent and what factors or people in their system have contributed to this.

Appendix F: Proportionate review confirmation

WoSRES
West of Scotland Research Ethics Service



Miss Claudia Willis
Trainee Clinical Psychologist
Cambridge and Peterborough NHS Foundation
Trust
Doctoral Programme in Clinical Psychology
University of East Anglia
Norwich
NR4 7TJ

West of Scotland REC 4

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhs.gov.uk

Date 22 July 2014
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Miss Willis

Study title:	Qualitative Exploration of how Young People Experience and Make Sense of Medically Unexplained Symptoms
REC reference:	14/WS/1049
Protocol number:	N/A
IRAS project ID:	148719

Thank you for your email of 22 July 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Evelyn Jackson, wosrec4@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [evidence of sponsor insurance]		09 May 2014
Interview schedules or topic guides for participants	1.3	23 June 2014
Letter from sponsor [sponsorship and indemnity letter]		26 June 2014
Letters of invitation to participant [Letter and permission to contact form]	1.3	23 June 2014
Non-validated questionnaire [participant demographic information form]	1.3	23 June 2014
Participant consent form [young person consent form (16-17 years)]	1.3	23 June 2014
Participant consent form [Parent/carers consent form]	1.3	23 June 2014
Participant consent form [young person assent form (11-15 years)]	1.3	23 June 2014
Participant information sheet (PIS) [Young Persons - clean copy]	1.4	16 July 2014
Participant information sheet (PIS) [16-17 yr olds]	1.1	16 July 2014
Participant information sheet (PIS) [Young Persons with tracked changes]	1.4	16 July 2014
REC Application Form [REC_Form_02072014]		02 July 2014
Referee's report or other scientific critique report [UEA project approval]		06 February 2014
Referee's report or other scientific critique report [UEA reviewers requested changes]		10 December 2013
Referee's report or other scientific critique report [Changes in response to reviewers comments]		07 January 2014
Research protocol or project proposal	1.3	23 June 2014
Response to Request for Further Information	-	22 July 2014
Summary CV for Chief Investigator (CI)		23 June 2014
Summary CV for student		23 June 2014
Summary CV for supervisor (student research)		23 June 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [flowchart summarising procedure]	1.3	23 June 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/WS/1049	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



For Dr Jackie Riley
Alternate Vice-Chair

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Mrs Sue Steel*
 Ms Ioanna Theophanous, Division of Research and Innovation, Joint
 R&D office for GOSH/ICH

Appendix G: Research and Development approval from Great Ormond

Street Hospital



UCL INSTITUTE OF CHILD HEALTH

Great Ormond Street 
Hospital for Children

NHS Foundation Trust

Joint Research and Development Office
Division of Research and Innovation

Direct Line: 020 7905 2698
Email: R&DGovernance@gosh.nhs.uk

29/08/2014

Dear Lisa,

Project Title	Qualitative Exploration of how Young People Experience and Make Sense of Medically Unexplained Symptoms
Protocol version	1.3
Protocol date	23 June 2014
REC Reference	14/WS/1049
R&D Reference	14HT03
Sponsor	University of East Anglia
Chief Investigator (CI)	Claudia Willis

Notification of Great Ormond Street Hospital NHS Permission.

The research approval process for the above named study has been completed successfully. I am pleased to issue approval, on behalf of Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- The Principal Investigator (PI) must ensure compliance with protocol and advise the Joint R&D Office of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the Joint R&D Office in line with the study protocol and Sponsor requirements. Adverse Incidents (AIs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.
- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.

Joint Research and Development Office
Division of Research and Innovation
UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH
Tel: 020 7905 2700 Fax: 020 7905 2201
www.gosh.nhs.uk

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Non-CTIMP Approval Letter v2.1

The child first and always

14HT03

- The PI must allow monitoring and auditing by the Sponsor and the Joint R&D Office.
- The PI must report any cases of suspected research misconduct and fraud to the Joint R&D Office.
- The PI must provide an annual report to the Joint R&D Office for all research involving NHS patients, staff and/or resources. The PI must notify the Joint R&D Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Joint R&D Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,



Manju Agarwal
Research Management and Governance Officer
Joint Research and Development Office

cc: GOSH Finance
Sponsor contact

Appendix H: Research and Development approval from Queen Elizabeth Hospital King's Lynn

The Queen Elizabeth Hospital 
King's Lynn
NHS Foundation Trust

The Queen Elizabeth Hospital
Gayton Road
Kings Lynn
Norfolk
PE30 4ET
www.qehkl.nhs.uk

Research and Development

Dr Parvez Moondi
Chair of the Research Governance Committee

R&D Co-ordinator – Karen Lupton
E-mail: karen.lupton@qehkl.nhs.uk

Tel: 01553 214571

LETTER RE-ISSUED 24- SEPTEMBER 2014 DUE TO TYPOGRAPHICAL ERROR

Miss Claudia Willis
Trainee Clinical Psychologist
Doctoral Programme in Clinical Psychology
University of East Anglia
Norwich
NR4 7TJ

Thursday 18- September 2014

Dear Miss Willis

R&D: 28/14
REC: 14/WS/1049
TITLE: How Young People Make Sense Of Medically Unexplained Symptoms

Thank you for sending the following documentation relating to the above study:

- Protocol Version 1.3 23.06.14
- Signed SSI - 148719/642769/6/491/239087/304623
- R&D Form – 148719/642751/14/223

This study has been reviewed by the Trust's Research Governance team and we can confirm that the Trust is willing for this work to take place. The following has also been noted in response to a question raised by one of our committee members, *"Identification of participants at your site will be led by Dr Eleanor Sutton, Clinical Psychologist. Other professionals who are staff members at QEH may also identify participants, for example paediatricians. I will not identify participants myself. I will only receive details of potential participants if they complete the consent to contact form, or contact me themselves"*.

I would like to take this opportunity to remind you that the Trust manages all research in accordance with the requirements of the Research Governance Framework and the Trust's Standard Operating Procedures.

In order to comply with the above, if the study is not completed within one year from the date of this letter, a report summarising the progress of the study should be submitted to the R&D Office. In the case of multi-centre studies this is usually provided by the Chief Investigator/Clinical Trials Unit. Alternatively, we can supply a blank form for you to complete: please contact us for a copy.

Chair: Edward Libbey
Interim Chief Executive: Manjit Obhrai
Patron: Her Majesty The Queen



**YOU ARE REQUIRED TO NOTIFY OUR R&D OFFICE THE DATE OF THE
FIRST PARTICIPANT SCREENED AND THE FIRST PARTICIPANT RECRUITED FROM OUR SITE**

ACCESS TO OUR TRUST BY AN EXTERNAL MEMBER OF THE RESEARCH TEAM:

If external members of the research team require access to our Trust in order to conduct their research activities then they must submit the relevant documentation to our R&D department in order to obtain a letter of access.

On completion of the project, please forward to the R&D Office any "final report" relating to the project – e.g. report from Chief Investigator/Clinical Trials Unit, copy of any published article, etc. Any reports resulting from the study, which may be produced at a later date, should also be forwarded, to ensure a complete record is held here.

Following documents received ethical approval from West of Scotland REC 4 dated 22 July 2014:

Interview schedules or topic guides for participants	1.3 23 June 2014
Letters of invitation to participant [Letter and permission to contact form]	1.3 23 June 2014
Non-validated questionnaire [participant demographic information form]	1.3 23 June 2014
Participant consent form [young person consent form (16-17 years)]	1.3 23 June 2014
Participant consent form [Parent/carer consent form]	1.3 23 June 2014
Participant consent form [young person assent form (11-15 years)]	1.3 23 June 2014
Participant information sheet (PIS) [Young Persons - clean copy]	1.4 16 July 2014
Participant information sheet (PIS) [16-17 yr olds]	1.1 16 July 2014
Participant information sheet (PIS) [Young Persons with tracked changes]	1.4 16 July 2014
Research protocol or project proposal	1.3 23 June 2014
Summary, synopsis or diagram (flowchart) of protocol in non - technical language [flowchart summarising procedure]	1.3 23 June 2014

If our department can be of any further assistance please do not hesitate to contact me.

Yours sincerely



Dr Parvez Moondi, Chair of the Research Committee

CC Dr Eleanor Sutton, Clinical Psychologist, The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
Ms Kiki Mastroyannopoulou, Academic Supervisor, University of East Anglia
Mrs Sue Steel, Research & Enterprise Services, University of East Anglia

Chair: Edward Libbey
Interim Chief Executive: Manjit Obhrai
Patron: Her Majesty The Queen



Appendix I: Parent/carers research information sheet



Parent/Carer Research Information Sheet

Project title: Young People's Understanding of their Symptoms

We would like to invite you and your child to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you and your child. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about ten minutes. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear.

What is the purpose of the study?

This study aims to investigate how young people make sense of symptoms for which doctors have been unable to find a clear medical explanation. We hope that if we can find out more about how young people understand these, we can find out more about what it is like to have these symptoms. This information will also help medical professionals understand young people's perspectives of their condition and adapt ways of working to make it most helpful for the young people involved.

Why have I been invited?

You have been invited because the clinic which manages your child's care has agreed to help with this research. That means that lots of families with a child with similar difficulties have been invited to take part. We aim to have about 12 young people taking part.

Do I have to take part?

No, it is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. As your child is aged 16 or under, we ask for your consent for them to take part, and also your child's permission or 'assent'. They will only be involved in the research if you both agree to this. You are free to withdraw at any time, without giving a reason. This would not affect the ongoing medical care you or your child receives.

What will happen to me if I take part?

You will take part in the research as a parent/carers, with most of the research focused on an interview with your child. We ask that your child meets with a

researcher at a time that is convenient for you, ideally attached to a clinic appointment so we can use a room there. If this is not possible, the researcher will arrange another time and location which is convenient for you, including at your home if you would prefer this.

You will be asked to wait outside the room for the duration of the interview, and complete a short form with some details of the symptoms your child has and different clinics/appointments you have attended. Your child will be asked to accompany the researcher into a private room. To help your child feel comfortable, there will be time set aside for questions, a short chat or an age-appropriate game. They will then be asked some questions by the researcher, in an informal interview. The interview will be audio-recorded. This interview will probably last for about 45 minutes. There will then be time at the end for your child to ask any questions, have a discussion about the interview or play an age-appropriate game. They will be free to stop the interview and leave if they wish to, or take breaks as they would like. The whole process should take up to one hour.

The audio-recording of the interview will then be transcribed by the researcher, and analysed. This research is part of the researcher's training programme in clinical psychology, and will be written as a thesis for the training. It may also be published as a research article.

Expenses and payments

It is not expected that you will have any expenses as a result of the study. The researcher will aim to meet you when you were attending the clinic anyway, and if an alternative needs to be organised, this will be with minimal disruption and cost to yourselves. As a "thank you" for taking part, each child participating will receive a ten pound voucher after the interview. If they begin the interview and then change their mind, they will still be given the voucher.

What will I have to do?

This is described in the section above: 'what will happen to me'. The research should be limited to the one interview. You and your child will not be asked to do anything else for this research. You can continue any support or clinical care as normal.

Possible advantages and risks

It is hoped this research may help improve interactions of medical professionals and young people with similar difficulties. However, it is not possible to provide individual feedback and the research may not benefit your child directly. It is hoped this research will improve the care of young people with similar difficulties in the future.

There are no specific risks with taking part in this research. However, there is a small possibility the interview may bring up some issues which may be distressing for your child. If this did happen, they would be offered a break or to

discontinue. They would also be offered time to think about this with the researcher. The researcher is a Trainee Clinical Psychologist which means they have clinical skills necessary for supporting people who are distressed. Although every effort is made to keep confidentiality, if your child discloses any information which makes the researcher concerned about the safety of your child or others, the researcher will be obliged to pass this information on to necessary people, which may include the clinical team and yourself.

There are also contact details at the end of this information sheet which you or your child can use.

Will my taking part in the study be kept confidential?

Yes – all data will be stored separately to consent forms which have your name on them. All data will be stored securely, and audio recordings will be saved onto a password protected memory stick. Individual data will not be discussed with your child's care team or anyone external to the study. If you attend Great Ormond Street Hospital, Dr Lisa Barkley, a Clinical Psychologist at the hospital is the lead investigator for this site and may look at anonymised data. Research supervisors at the University of East Anglia may look at data connected to this study.

When writing up the research, the researcher will include some quotes from the interviews. Any names and places will be changed to reduce the chance of identification, but there is a possibility that you, your child or people who know you well may be able to identify themselves from these quotes.

What if there is a problem?

In the unlikely event that you are upset by taking part in any research project, there are no special compensation arrangements. If you are harmed by someone's negligence you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints procedure is available to you. You may also complain to Professor Ken Laidlaw at the University of East Anglia who is external to this project. His contact details are at the end of this information sheet, in the contact details section.

In the event that you or your child become distressed while participating in this research, please contact the researcher, your GP services or clinical care contact. The details of your regular team are at the bottom of this page. If this is outside of normal working hours please contact your out of hours GP service, NHS direct (0845 4647) or Childline (0800 1111).

What will happen if I don't want to carry on with the research?

You can change your mind about taking part in the research at any point. If you or your child decide you don't want to carry on, please let the researcher or a member of your clinical care team know as soon as possible. Your child can

have a break or leave the room at any point during the interview without giving a reason. They will be supplied with a card which they can show the researcher to ask them to stop, as not all young people will feel able to tell the researcher. You can still change your mind after the interview if you decide you would not like any of the conversation in the interview included in the research.

Where and how long will records be stored?

Data will be stored in locked cabinets in local health care or university premises. It will be kept for five years after the completion of the study and then destroyed.

What will happen to the results of the research study?

The results of the study will be reported as anonymous data. The study will be seen by colleagues and supervisors at the University of East Anglia, and other members of the research team. Results may also become available more publicly if the research is published, however no identifiable material will be published. Your child may request an update about the results by providing their address on the assent form.

Who is organising and funding the research?

The study has been designed by Claudia Willis (Trainee Clinical Psychologist at the University of East Anglia), and her research supervisors. The research is being carried out as part of training for a Doctorate in Clinical Psychology. The research has clinical collaborators: Dr Lisa Barkley and her team at Great Ormond Street Hospital, and Dr Eleanor Sutton and her team at the Queen Elizabeth Hospital, Kings Lynn.

Who has reviewed the study?

The research has been considered and approved by the NHS Research Ethics Committee. The research has also been reviewed and approved by the University of East Anglia.

Further information and contact details

This information sheet will be discussed with you and your child by a researcher. You will have an opportunity to ask any questions then, or at any point after you consent.

If you would like any more information about the study or need to contact the researcher, please feel free to contact

Claudia Willis (Trainee Clinical Psychologist):

Doctoral Programme in Clinical Psychology, Elizabeth Fry Building

University of East Anglia

Norwich

Norfolk

NR4 7TJ

Email: Claudia.willis@uea.ac.uk

Alternatively, you could contact

Kiki Mastroyannopoulou

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich

NR4 7TJ

Tel: +44 (0)1603 59 1890

Email: K.Mastroyannopoulou@uea.ac.uk

If you have a complaint about the research, or would like to speak to someone external to the study, please contact

Professor Ken Laidlaw

Doctoral Programme in Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich

NR4 7TJ

Tel: +44 (0)1603 59 1890

Email: k.laidlaw@uea.ac.uk

For independent advice on participating in research, you can also contact your local Patient Advice and Liaison Service (PALS) at the hospital where you usually attend appointments.

You can also contact the team you see regularly on:

Address:

Phone number:

Email address:

Appendix J: 16-17 year old participant research information sheet



Research Information Sheet for 16-17 year olds

Project title: Young People's Understanding of their Symptoms

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve. One of our team will go through the information sheet with you and answer any questions you have. This should take about ten minutes. Talk to others about the study if you want to.

Please ask us if there is anything that is not clear.

What is the purpose of the study?

This study aims to investigate how young people make sense of symptoms for which doctors have been unable to find a clear medical explanation. We hope to find out more about how young people understand these and what it is like to have these symptoms. This information will also help medical professionals understand young people's perspectives of their condition and adapt ways of working to make it most helpful for the young people involved.

Why have I been invited?

You have been invited because the clinic you go to has agreed to help with this research. That means that lots of young people with similar difficulties have been invited to take part. We aim to have about 12 young people taking part.

Do I have to take part?

No, it is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You can change your mind about taking part at any time, without giving a reason. This would not affect your ongoing medical care.

What will happen to me if I take part?

You will be asked to have an interview with a researcher (Claudia Willis). We will arrange this at a time that suits you, ideally attached to a clinic appointment so we can use a room there. If this is not possible, the researcher will arrange another time and location that is convenient for you, including at your home if you would prefer this.

Your parent/carer will be asked to wait outside the room during the interview, and complete a short form with some details of your symptoms and different

clinics/appointments you have attended. To help you feel comfortable, there will be time for questions, a short chat or an age-appropriate game, maybe on a laptop or iPad. You will then be asked some questions by the researcher, in an informal interview. What we say will be recorded. This interview will probably last for about 45 minutes. There will be time at the end for you to ask any questions, have a discussion about the interview or play an age-appropriate game. You can stop the interview and leave or take a break anytime you want to. The whole process should take up to one hour.

The audio-recording of the interview will then be transcribed (what we say in the interview is typed so we have a written version) by the researcher, and analysed. This research is part of the researcher's training programme in clinical psychology, and will be written as a thesis (like a piece of coursework) for the training. It may also be published as a research article.

Expenses and payments

It is not expected that you will have any expenses as a result of the study. The researcher will aim to meet you when you were attending the clinic anyway, and if an alternative needs to be organised, this will be with minimal disruption and cost to yourselves. As a "thank you" for taking part, you will receive a ten pound voucher after the interview. If you begin the interview and then change your mind, you will still be given the voucher.

What will I have to do?

This is described in the section above: 'what will happen to me'. The research should be limited to the one interview. You will not be asked to do anything else for this research. You can continue any support or clinical care as normal.

Possible advantages and risks

It is hoped this research may help improve the way medical professionals talk to and support young people with similar difficulties. However, we cannot provide individual feedback and the research may not benefit you directly. It is hoped this research will improve the care of young people with similar difficulties in the future.

There are no specific risks with taking part in this research. However, there is a small possibility the interview may bring up some issues that may be difficult. If this does happen, you would be offered a break or to stop. You would also be offered time to think and talk about this with the researcher. The researcher is a Trainee Clinical Psychologist which means they have skills for supporting people who are upset. Although we try to keep everything we talk about confidential and without any information that identifies you, if you disclose any information that makes the researcher concerned about the safety of you or others, the researcher will have to pass this information on to necessary people. This may include the clinical team and your parent/carer.

There are also contact details at the end of this information sheet that you can use.

Will my taking part in the study be kept confidential?

Yes – all data (interviews and transcripts) will be stored separately to consent forms that have your name on them. All data will be stored securely, and audio recordings will be saved onto a password protected memory stick. Individual data will not be discussed with your care team or anyone external to the study. If you attend Great Ormond Street Hospital, Dr Lisa Barkley, a Clinical Psychologist at the hospital is the lead investigator for this site and may look at anonymised data (without your name or details). Research supervisors at the University of East Anglia may look at data connected to this study.

When writing up the research, the researcher will include some quotes from the interviews. Any names and places will be changed to reduce the chance of identification, but there is a possibility that you or people who know you well may be able to identify you from these quotes.

What if there is a problem?

In the unlikely event that you are upset by taking part in any research project, there are no special compensation arrangements. If you are harmed by someone's negligence you may have grounds for legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of the study, you can use the normal National Health Service complaints procedure. You may also complain to Professor Ken Laidlaw at the University of East Anglia who is external to this project. His contact details are at the end of this information sheet, in the contact details section.

In the event that you become distressed while participating in this research, please contact the researcher, your GP services or clinical care contact. The details of your regular team are at the bottom of this page. If this is outside of normal working hours please contact your out of hours GP service, NHS direct (0845 4647) or Childline (0800 1111).

What will happen if I don't want to carry on with the research?

You can change your mind about taking part in the research at any point. If you decide you don't want to carry on, please let the researcher or a member of your clinical care team know as soon as possible. You can have a break or leave the room at any point during the interview without giving a reason. You will have a card you can show the researcher to ask them to stop, if you don't want to say stop. You can still change your mind after the interview if you decide you would not like any of the conversation in the interview included in the research.

However, once the analysis has been completed we cannot remove individual data.

Where and how long will records be stored?

Data will be stored in locked cabinets in local health care or university premises. It will be kept for five years after the completion of the study and then destroyed.

What will happen to the results of the research study?

The results of the study will be reported as anonymous data (without any names or identifying information). The study will be seen by colleagues and supervisors at the University of East Anglia, and other members of the research team. Results may also become available more publicly if the research is published, however no identifiable material will be published. You can request an update about the results by providing your address on the consent form.

Who is organising and funding the research?

The study has been designed by Claudia Willis (Trainee Clinical Psychologist at the University of East Anglia), and her research supervisors. The research is being carried out as part of training for a Doctorate in Clinical Psychology. The research has clinical collaborators: Dr Lisa Barkley and her team at Great Ormond Street Hospital, and Dr Eleanor Sutton and her team at the Queen Elizabeth Hospital, Kings Lynn.

Who has reviewed the study?

The research has been considered and approved by the NHS Research Ethics Committee. The research has also been reviewed and approved by the University of East Anglia.

Further information and contact details

This information sheet will be discussed with you by a researcher. You can ask any questions then, or at any point after you consent.

If you would like any more information about the study or need to contact the researcher, please feel free to contact

Claudia Willis (Trainee Clinical Psychologist):

Doctoral Programme in Clinical Psychology, Elizabeth Fry Building

University of East Anglia

Norwich

Norfolk

NR4 7TJ

Email: Claudia.willis@uea.ac.uk

Alternatively, you could contact

Kiki Mastroyannopoulou

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich

NR4 7TJ

Tel: +44 (0)1603 59 1890

Email: K.Mastroyannopoulou@uea.ac.uk

If you have a complaint about the research, or would like to speak to someone external to the study, please contact

Professor Ken Laidlaw

Doctoral Programme in Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich

NR4 7TJ

Tel: +44 (0)1603 59 1890

Email: k.laidlaw@uea.ac.uk

For independent advice on participating in research, you can also contact your local Patient Advice and Liaison Service (PALS) at the hospital where you usually attend appointments.

You can also contact the team you see regularly on:

Address:

Phone number:

Email address:

As a “thank you” for taking part, you will receive a ten pound voucher after the interview. If you begin the interview and then change your mind, you will still be given the voucher.

Appendix K: 11-15 year old participant research information sheet



Young Person Research Information Sheet

Project title: Young People's Understanding of their Symptoms

My name is Claudia and I am doing a project about what it is like for young people to have difficult symptoms, and what they think about them. I have to do this project as part of my work at the University of East Anglia. I'm asking if you want to join in because you have symptoms like this.

Its up to you if you say YES or NO. Read this first. Talk to your family, friends, doctor or nurse if you want to.

Why are we doing this research?

We think it's important that people working with young people who have difficult symptoms understand what they think and what its like.

Do I have to take part?

NO. It is up to you, and your parent/carers. It is good if you chat to them about this. You can change your mind or stop taking part anytime and you don't have to tell us why. You can still keep seeing your doctor, nurse, psychologist or anyone else you see at the hospital.

What will happen if I take part?

You will meet me (Claudia) for about an hour. We will have a chat about things you like, or play a game you like, maybe on an iPad or computer. Then we will talk about your symptoms for about half an hour. It should feel like a chat. We will record the sound of what we are saying. You can take a break or stop anytime.

After we can talk some more, you can ask questions, or play a game.

Is there anything to be worried about?

We hope not. There is a small chance you might find some of the questions a little upsetting. If this happens it is ok to tell me (Claudia) or take a break. There is time at the end of the interview to talk about this.

What are the good things about taking part?

I don't know that the research will mean good things for you. But we hope it can help other young people in the future.

What happens when the research stops?

When the research stops, I will look at all of the chats with young people. I will write about the research for my training, and it might be published as a journal article later. Journal articles are normally read by doctors, nurses and other professionals.

All information we have, like recordings of our chat will be stored securely so other people can't look at them. They might be checked by people who make sure the research has done everything it should.

What happens if something goes wrong or there is a problem?

It is ok to change your mind about taking part ANYTIME. If something goes wrong or there is a problem before or after the interview, please talk to your parent/carer, someone you know at the clinic or me. If it is during the interview, please tell me.

If you get upset, worried or need extra support, tell your parent/carer, a member of the clinical team or your GP. If it is in the evening/night or at weekends you can call your out of hours GP service, NHS direct (0845 4647) or Childline (0800 1111).

Will anyone else know I am doing this?

We try to make it so other people don't know you're doing this, or what you say in your interview. But your clinical team will know you are taking part in the research, and so will your parent/carer.

When I write about the research, I will change your name and any names or places you talk about. I will use quotes of the interviews, writing some things you said. This means you or others close to you might be able to work out which bits you said because of your way of talking.

We use the same rules you use during your clinical appointments. If you tell me something which makes me worried about your safety or the safety of other people, I do have to tell other people about this. We only tell the people who need to know, maybe your parent/carer and your clinical team.

Who is organising this research?

The study has been designed by Claudia Willis (Trainee Clinical Psychologist at the University of East Anglia), and her research supervisors (they are a bit like my teachers). The research is being

carried out as part of training for a Doctorate in Clinical Psychology. This means Claudia has been working in Psychology for a little while, and is doing training to be a clinical psychologist, like the one you see at the hospital. Claudia has to do research for the training.

Who has reviewed this study?

Some people have to check the research to make sure it's ok. The NHS Research Ethics Committee, the research team at the hospital you go to and the University of East Anglia have said its ok.

Contact Details

If you want to find out more or need to contact the researcher, please contact

Claudia Willis (Trainee Clinical Psychologist):

Doctoral Programme in Clinical Psychology

Elizabeth Fry Building

University of East Anglia

Norwich

Norfolk

NR4 7TJ

Email: Claudia.willis@uea.ac.uk

Or you could contact:

Kiki Mastroyannopoulou

Doctoral Programme in Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich

NR4 7TJ

Tel: +44 (0)1603 59 1890

Email: K.Mastroyannopoulou@uea.ac.uk

If you have a complaint about the research, or would like to speak to someone outside the study, please contact

Professor Ken Laidlaw

Doctoral Programme in Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich

NR4 7TJ

Tel: +44 (0)1603 59 1890

Email: k.laidlaw@uea.ac.uk

[You could also contact the local Patient Advice and Liaison Service \(PALS\) at the hospital you usually go to.](#)

You can also contact the team you see regularly on:

Address:

Phone number:

Email address:

At the end you get a ten pound voucher to say thank you. If you start talking and then change your mind, you still get the voucher.

Appendix L: Parent/carer research consent form

Parent/Carer consent form

Version 1.3

23/06/2014



Parent/Carer Consent Form

Project title: Young People's Understanding of their Symptoms

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: An Exploration of Young People's Understanding of their Symptoms

Name of Researcher: Claudia Willis, Trainee Clinical Psychologist, University of East Anglia

Please Initial all boxes

1. I confirm that I have read and understand the information sheet dated [\[23/06/2014\]](#) (version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my and my child's participation is voluntary and that I or my child are free to withdraw at any time without giving any reason, without our medical care or legal rights being affected. ☐
3. I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from the University of East Anglia, from regulatory authorities or from the NHS Trust, where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my child's interview being audio-recorded, and understand quotes of this may be included in writing about the research, in the researcher's thesis and/or a published article. ☐
5. I agree for my child to take part in the above study. ☐

Name of Parent/Carer and child

Date

Signature

Name of Person
taking consent.

Date

Signature

Appendix M: 16-17 year old participant research consent form

Young person consent form

Version 1.3

23/06/2014



Young Person Consent Form (16-17 years)

Project title: Young people's understanding of their symptoms

Young person to circle all they agree with:

Has somebody explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Are you happy to take part?	Yes/No
Are you happy for our voices to be recorded during the interview?	Yes/No

If any answers are "no" or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name

Date

If you would like to find out what the research found afterwards, please write your address here:

The person who explained this project to you needs to sign too:

Print Name

Sign

Date

Thank you for your help.

Appendix N: 11-15 year old participant research assent form

Young Person Assent Form

Version 1.3



Young Person Assent Form (11-15 years)

Project title: Young people's understanding of their symptoms

Child (or if unable, parent on their behalf) /young person to circle all they agree with:

- | | |
|---|--------|
| Has somebody else explained this project to you? | Yes/No |
| Do you understand what this project is about? | Yes/No |
| Have you asked all the questions you want? | Yes/No |
| Have you had your questions answered in a way you understand? | Yes/No |
| Do you understand it's OK to stop taking part at any time? | Yes/No |
| Are you happy to take part? | Yes/No |
| Are you happy for our voices to be recorded during the interview? | Yes/No |

If any answers are "no" or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name

Date

If you would like to find out what the research found afterwards, please write your address here:

The person who explained this project to you needs to sign too:

Print Name

Sign

Date

Thank you for your help.

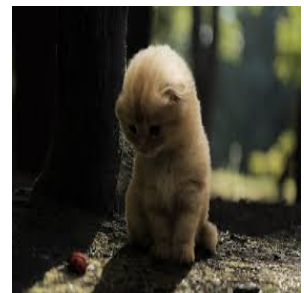
Appendix O: Summary of results sent to participants

Hello (name)

Thank you for helping out with the research about talking about your symptoms. You asked to have some feedback from the research, so I am sending you this. Like we said before, this is general feedback. This means it's from everyone's interviews together and not just yours.

The main things we found were:

- Young people in the research found it hard talking about their symptoms. Most weren't really sure what to call them so didn't have the words to talk about their symptoms to help others understand them.
- Young people in the research didn't really have an explanation for their symptoms that made sense to them or that they understood and really believed was right for them.
- Not really knowing about symptoms is difficult, and made most people worried and frustrated.
- A lot of young people in the research had times when they felt others didn't believe them about their symptoms.
- People felt alone with their symptoms and wondered if there were other young people having similar things happen to them.
- A lot of participants worried that they were weird or not normal.
- These symptoms affected life, with most young people missing at least some school and having to stop a lot of things they like doing and were also going out with friends less.
- It was really hard trying to find your way through all the different doctors and hospitals and was quite confusing. A lot of the time it felt like doctors were talking to your parents not you, and you didn't really understand the doctors.
- Everyone was looking to the future in some way, wondering what their symptoms would be like in the



future and looking for ways to manage symptoms and move on.

- A lot of young people in the research felt that as doctors didn't really know what was going on or how to make them better, it was up to them. But they weren't sure how to do this.

Everyone who took part talked about wanting to make everything better and easier for others with similar symptoms, and I am working hard on writing all this up to try and do this.

Thank you for giving your time and talking about things that are sometimes difficult to help do this. I couldn't have done this research without you!

Wishing you and your families all the very best for the future!

Claudia

Claudia Willis
Trainee Clinical Psychologist

